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TITLE: A Study of Black and White Men with a Family History of

Prostate Cancer

PRINCIPAL INVESTIGATOR: Roshan Bastani, Ph.D.

Dr. Annette Maxwell

CONTRACTING ORGANIZATION: University of California, Los Angeles

Los Angeles, California 90024-1406

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endorse many barriers to screening or significant cancer-related distress. Most relatives had some knowledge of risk factors. The vast majority reported having a digital rectal exam sometime in their life (76%) however less had one during the past year. Prostate specific antigen (PSA) testing receipt was lower. Fifty-six percent of relatives reported having had a PSA test sometime in their lifetime whereas 43% reported having a PSA test during the last year. Demographic, knowledge, and attitudinal factors emerged as bivariate

and multivariate predictors of PSA receipt in the past year.

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#### INTRODUCTION

The purpose of this study was to conduct telephone surveys with first degree relatives of prostate cancer cases to obtain information on knowledge, behavior and psychological distress associated with risk status. The research questions that were addressed included: What do highrisk men know about prostate cancer? What is the level of psychological distress associated with knowledge of risk status? What is the personal cost-benefit ratio for these men when balancing their increased risk for the disease against the morbidity associated with treatment? What are the rates of usage of DRE and PSA in this population? What are the prevalent attitudes and beliefs in this group regarding prostate cancer screening and participation in clinical trials? Are there differences in knowledge, attitudes, behaviors, and psychological distress between different ethnic groups? What demographic, health care system, knowledge, and attitude factors are related to participation in screening and willingness to participate in clinical trials? We used a population-based cancer registry, the Cancer Surveillance Program (CSP) of Los Angeles, to obtain a sample of prostate cancer cases diagnosed in Los Angeles County over a four year period (1997-2000). We contacted cases to request relative information. Then we contacted relatives and asked them to participate in a brief survey, by telephone, on prostate cancer. We planned to conduct surveys with 250 African American and 250 White relatives. The study was continuously approved by the UCLA Human Subject Committee throughout its course.

#### FINAL REPORT BODY

The funding for this study was received at the end of October 1998, which reduced the first year of the study to 10 months, causing some of the first year's activities to extend into Year 2. In Year 2 we were able to complete all of Task 1 and get well into activities related to Tasks 2, 3 and 5. In the first 6 months of year 3, we completed Tasks 2, 3, and 5. We focused on Tasks 4 and 6 during the no-cost extension. The following section describes some of the major accomplishments associated with each task.

#### Task 1

#### **Questionnaire** (Appendix 1)

In the first year of the study, we conducted a total of 13 focus groups with men from four ethnic groups (52 African-American, 39 Caucasian, 29 Hispanic, 20 Filipino). We also pilot tested the telephone survey with 80 prostate cancer cases and their relatives. Using our focus group and pilot findings, we modified and finalized our survey. It was translated into Spanish and programmed into our Computer Assisted Telephone Interviewing (CATI) database in both languages. The following domains, based on the Adherence Model, were included in the survey:

- 1. Medical History
- 2. Family History of Prostate Cancer
- 3. Psychological Distress
- 4. Past Adherence
- 5. Communication with Doctor
- 6. Demographics
- 7. Knowledge of Risk Factors
- 8. Perceived Susceptibility
- 9. Beliefs in Benefits vs. Costs
- 10. Subjective Norms
- 11. Fatalism
- 12. Social Supports
- 13. Barriers and Facilitators
- 14. Knowledge of Screening Guidelines
- 15. Past Participation, Intentions & Knowledge of Clinical Trials
- 16. Demographics
- 17. Health Care Benefits & Coverage

#### Task 2:

#### Recruitment

a) Development of ethnically specific recruitment materials (Appendix 2)

We used focus group participant suggestions to develop full-color ethnically specific recruitment materials. We designed separate tri-fold pamphlets for cases and relatives. These pamphlets included information about the purpose of the study and what participation would entail for cases and relatives. Separate pamphlets were designed for each ethnicity (African-American, Asian, White, and Hispanic) and displayed a culturally relevant graphic theme designed to emphasize the specificity of the study to each ethnic community.

#### b) Cases received from the California Tumor Registry

In total, we received 14,661 prostate cancer cases from the registry (after deleting duplicates) that were still alive. Five thousand three hundred and eighteen cases were diagnosed in 1997, 4577 cases in 1998, 4248 in 1999, and 518 in 2000. As mentioned in our previous annual reports, originally we had proposed to contact cases diagnosed in 1998 and 1999. However, we expanded our recruitment criteria to include 1997. This turned out to be beneficial for the study overall, because reporting of the 1997 cases was much more complete than that of the 1998 cases at the time when we requested these cases. In addition, we obtained available non-white cases diagnosed in 2000 to increase our sample in selected ethnic groups. We received new cases from the Los Angeles Cancer Surveillance Program approximately every two months throughout the course of the project until we discontinued receipt of new cases in January of 2001. We sent 5197 letters (and if needed a second request letter) to physicians to inform them of the study. Physicians of 123 patients recommended we not contact the cases for various reasons, and 110 cases were identified as deceased through physician contact.

#### c) Cases Contacted

Although we were funded to conduct the study with only African American and White men, we expanded the study to Hispanic and Asian men as well, because of the dearth of existing information on these groups. We contacted a total of 1054 African American cases, 700 Hispanic cases, 973 Asian cases, and 1276 White cases (4003 total cases contacted). Stratified random sampling was used to select White cases in all years. Age was used as the stratifying variable, with 20% of cases being selected from those diagnosed before age 60. Of cases contacted, 1232 did not provide relatives due to the following reasons; case deceased, language ineligible, had no eligible relatives, living outside the US, health problem prevented telephone contact, or no history of prostate cancer. For 636 cases, we did not have valid contact information and were unable to obtain the appropriate information. For an additional 386 cases, we were unable to reach them by mail or by telephone after 10 attempts. We recruited a total of 299 African American, 203 Hispanic, 231 Asian, and 412 White cases (1145 total cases) that provided information on at least one male relative between the ages of 40-75. An additional 604 cases refused to provide information about their first-degree relatives resulting in a refusal rate of 35% (604/1749).

#### d) Relatives Recruited

We received information regarding a total of 653 African American, 457 Hispanic, 498 Asian, and 807 White **relatives** from consenting index cases. Of these, 468 African Americans, 314 Hispanics, 281 Asians, and 531 Whites were eligible for our study based on age, language,

and no previous history of prostate cancer. We contact, by mail or telephone, these 1594 relatives.

#### Task 3

#### **Interviewers**

In year 1 we recruited and trained a total of 6 part-time interviewers for this project. We hired at least one interviewer to match each ethnic group and several interviewers were English-Spanish bilingual. In year 2, due to the large volume of cases and relatives needed to be contacted in a timely manner (and some attrition in our interviewer staff), we hired and trained an additional 6 interviewers. In Year 3 we had 5 interviewers remaining and trained 3 additional interviewers to help complete the remaining surveys and recruitment calls. In year four we had 3 interviewers remaining and hired several additional interviewers to work on the present study and a second study utilizing telephone interviews.

Interviewers were supervised during all day, evening, and weekend shifts. A 5% random sample of respondents were called back to verify that the interview was conducted. Interviewers were debriefed on a monthly basis and retrained as necessary.

#### **Telephone Interviews**

We completed a total of 1029 surveys (272 African American, 228 Hispanic, 175 Asian, 354 Whites.) One hundred forty-eight of the contacted relatives did not speak English or Spanish, reported having had prostate cancer, were deceased, could not completed interview due to health problem, reported being either younger than 40 or older than 75, were not related by blood to the case, or were no longer living in the country. For sixty-eight relatives we had inaccurate contact information and were not able to locate the correct information. There were also a significant percentage of relatives (19% of contacted relatives) that did not respond to our invitation by mail and whom we were not able to reach by telephone after 10 attempts. One hundred and twelve relatives refused to participate resulting in a refusal rate of 10% (112/1141). We adapted our telephone survey into a brief mail survey in the hope of reaching some of these hard-to-reach relatives (See Appendix 3). The mailed survey contained the following items, also found in the telephone survey:

- age
- health history
- family history
- screening tests and recency of last test (if ever)
- education
- country of birth
- years in the U.S.
- ethnicity
- income

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- marital status
- date of birth
- likelihood of getting screened within 12 months
- participation in clinical trials
- health insurance status

Thirty-one relatives completed the mailed survey. These relatives are included in the 1029 completed surveys reported above.

## Task 4

## Validation of Self-Reported Screening

A validation form was developed to obtain information from subjects' physicians regarding the dates of receipt of Prostate Specific Antigen (PSA) testing in order to validate subject self-report. The validation forms were sent to all subjects with complete contact information (N = 1003). This mailing was started in the spring of 2000 and the last mailing to relatives was completed in January of 2002. The validation form utilized required the signature of each patient, to authorize release of his or her medical information. Initially we sent a letter to every relative that completed the survey requesting written permission to contact his health care provider for validation (see Appendix 4). Later we decided to request verbal permission from relatives during the telephone interview before sending the letter to the relative to request written permission (see Appendix 5). From that point forward, we sent letters requesting written permission for validation only for those relatives who verbally consented during the interview. Reminder letters were mailed to subjects as necessary. Two Hundred Eight-Eight relatives signed the validation form and returned it to us. When the signed validation form was returned to us, we in turn mailed it to their noted physician to obtain the screening information. If necessary, follow-up calls were placed to physicians who did not return the form. See Appendices 4-7 for the validation letters to subjects, physicians and the validation form. All 288 validation forms were sent to physicians requesting validation of self-reported screening behavior through medical record review. Two weeks following the initial mailings to providers requesting validation information, follow-up reminder calls were conducted to remind physicians that did not respond to our mailing to provide validation information. Validation information was obtained for a total of 240 relatives out of the 288 who consented to the validation process through mail and telephone contact with physicians (83% of relatives who consented to validation).

#### Task 5

#### **Database Management**

Project staff conducted regular checks and clean up of our tracking databases for case and relative recruitment for accuracy and consistency of data entry and data coding. Survey data were collected using Computer Assisted Telephone Interviewing (CATI), thereby reducing interviewer error in following questionnaire skip patterns (skips are made automatically by the computer); eliminating out of range responses and missing data (a valid response is required in

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order to proceed to the next screen); eliminating the need for coding of most data; and providing immediate access to response frequencies at any time-point in the project. The CATI system generates daily production statistics and detailed reports of interviews completed during the session as well as refusals, scheduled call backs, and non-working phone numbers.

#### Task 6

#### Final Analysis and Report Writing

During year 4 (i.e., no cost extension period) the final analysis and final report were completed. The following were completed in regards to this task: conducted item analysis of measures to ensure adequate psychometric properties, examined clustering of responses within family units, intraclass correlations among key variables, and conducted logistic regression analyses, and examined data from the validation study to determine the extent of correspondence between self-reports and chart data.

#### KEY RESEARCH ACCOMPLISHMENTS

- finalized the questionnaire
- translated questionnaire into Spanish
- finalized the Computer Assisted Telephone Interviewing (CATI) program
- adapted the survey questionnaire into a brief survey to mail to difficult to reach relatives
- translated the brief mail survey into Spanish
- obtained prostate cancer cases diagnosed in 1997, 1998, 1999, and 2000
- contacted physicians of cases diagnosed in 1997, 1998, 1999, and 2000
- developed tracking databases for case and relative recruitment
- trained an additional group of male and female interviewers in study objectives, content of telephone survey, basic probing techniques, cultural sensitivity and communication skills, respondent follow-up protocols and CATI operations
- recruited and completed surveys with a total of 1029 eligible relatives
- obtained permission of 282 relatives to validate self-report of screening through physician verification/medical record review
- validation information was obtained for 210 of 282 consenting relatives (83% of consenting relatives)
- completed analyses and final report

#### REPORTABLE OUTCOMES

### **Sample Characteristics**

Characteristics of the baseline sample in percentages are represented below in Table 1. Overall, the majority of the sample was married (79%), over the age of 60 (74%), had at least a college education (70%), and had an income of \$55,000 or higher (57%). Chi-square analyses revealed ethnic differences for education, income, and proportion of sample born in the U.S. In general, White and Asian relatives had the highest levels of education and income. As expected, Hispanic and Asian relatives had had a substantial proportion of relatives born outside of the U.S..

Table 1 Demographic Characteristics of Baseline Respondents.<sup>1</sup>

Variable	White (N = 354)	Black (N = 272)	Hispanic (N = 228)	<b>Asian</b> (N = 175)	<b>Total</b> (N = 1029)
Age in years	% of sample	% of sample	% of sample	% of sample	% of sample
Age ≤ 60	24	31	22	25	26
Age > 60	76	69	78	75	74
Education					
High school and below	24	3.7	47	9	30
College and above	76	63	53	91	70
Incomes*					
Below \$55K	31	57	- 57	33	43
\$55K and above	69	43	43	67	57
Marriage					
Yes	80	75	80	85	79
No	20	25	20	15	21
Born in U.S.					
Yes	94	98	58	47	79
No	6	2	42	53	21

<sup>1</sup> Shaded areas indicate significant Chi-squared test p < .05.

#### Health Insurance

Overall, the majority of our sample had some type of health insurance (86%) and of those, the majority reported that their health insurance would cover the cost of a PSA test (60%). Chi-square analyses revealed numerous ethnic differences in regards to insurance variables. In general, Blacks and Hispanics reported the highest rate of being uninsured. White relatives reported the highest rate of fee-for-service insurance.

Table 2. Health Insurance Questions.<sup>2</sup>

Question		Response	<b>White</b> (N = 354)	Black (N = 272)	Hispanic (N = 228)	<b>Asian</b> (N = 175)	<b>Total</b> (N =1029)
			%	%	%	%	%
Health		Uninsured	7	11	16	6	10
Insurance		Other:	90	82	79	92	86
Type <sup>3</sup>	001	HMO	39	61	. 54	50	.50
Q81-	Q81- Q84c	PPO	31.	25	21	21	26
		FFS	43	32	33	33	37
		Medicare	16	22	14	22	18
		Medicaid	4	10	7	7	6
Does your		No	5	2	2	3	3
health		Yes	58	58	53	60	60
insurance cover PSA?	Q85	Not Insured	7	11	15	6	9
		Don't Know	30	20	31	31	28

<sup>2</sup> Shaded areas indicate significant Chi-squared test p < .05.

<sup>3</sup> These column percentages do not sum to 100%, due to the fact that there is overlap between groups.

# **Barriers to Screening**

Table 3 includes the percentage of the sample endorsing barriers to screening by ethnicity and across the sample as a whole. Overall, the majority of the sample did not endorse many barriers to screening such as cost, problems with transportation to clinic, or fear that PSA would show cancer. Chi-square analyses indicated a number of significant ethnic differences in reported barriers to prostate cancer screening. Blacks and Hispanics were most likely to report that they would have difficulty paying for a PSA test. Barriers were added up into a barrier score that was used in the multivariate prediction of PSA screening status (see page 26).

Table 3. Reported Barriers to Prostate Cancer Screening.<sup>4</sup>

Question		Response	White (N =354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
		%	%	%	%	%	%
Aware should get DRE yearly?	Q62	No Yes	39 61	46 64	52	51	45 55
Know should get PSA yearly?	Q63	No Yes	53	51 49	56 44	50.00	50
Fearful of getting tested?	Q64	Not Yes Yes	91	92 8	<b>89</b>	84 16	90
Is getting PSA important to you?	Q65	Not Yes Yes	15 85	86	86	16 84	15 85
Difficult to pay for PSA?	Q66	Not Yes Yes	91	82 18	80	90	87 14
Worried PSA show cancer?	Q67,	Not Yes Yes		90	77 23	76 24	83 17
Curable if found early?	Q68	Not Yes Yes	9 91	10 90	7 93	5 95	8 92
Can DRE cause sex problems?	<b>Q7</b> 0	Not Yes Yes	99	94	16 16	96	94
Have problem with doctor transportation?	Q71	Not Yes Yes	98	95 5	97	97	97
Only need PSA if recommended?	Q72	Not Yes Yes	81	73 28	36	43	30

<sup>4</sup> Shaded areas indicate significant Chi-squared test p < .05.

# **PSA Testing**

Although there are no official screening guidelines for PSA at this time, the majority of respondents (77%) believed that high risk men such as themselves should begin to have PSA tests beginning no later than age 40 and 75% reported that men should have at least one PSA test every year.

Table 4. PSA Testing. <sup>5</sup>

Question		Response (N = 354)	White (N =272)	Black (N = 272)	Hispanic (N = 228)	<b>Asian</b> (N = 175)	Total (N=1029)
At what age		30	15	30	23	20	22
should a		40	60	55	58	46	56
high-risk	007	50	22	14	16	27	20
man have his first PSA?	Q86	60	3	2	3	7	3
How often		Every 6 m	3	11	6	17	7
should a		Yearly	76	75	78	71	75
man such as	രാത	2-3 Years	18	12	11	20	15
yourself have a PSA?	ourself Q87	> 3 Years	3	3	11	4 :	33

<sup>5</sup> Shaded areas indicate significant Chi-squared test p < .05.

# Social Factors and Screening

The majority of our sample reported that at least some members of their social network get prostate cancer screening (86%). Approximately 45% of the sample reported discussing their personal risk for getting prostate cancer with their friends and family and 46% reported discussing their personal risk for getting prostate cancer with their physician. Chi-square analyses revealed significant ethnic differences on social factors. Hispanic relatives were least likely to report that their family members and/or friends received prostate cancer screening.

Table 5. Social Factors and Screening.<sup>6</sup>

Question		Response (N=354)	White (N=272)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
			%	%	%	%	%
How many friends and		Most	38	29	16	33	30
family get	Q77	Few	56	. 60	56	54	57
checked for prostate cancer?		None	6	12	28	14	14
Have you		No	54	52	59	62	56
discussed personal risk with friends and family?	Q79	Yes	46	49	41	38	44
Have you discussed		No	51	52	59	53	54
personal risk Q8 with your doctor?	Q80	Yes	49	48	41	48	46

<sup>6</sup> Shaded areas indicate significant Chi-squared test p < .05.

## **Risk Factor Beliefs**

Across the total sample, the majority of relatives accurately identified known risk factors for prostate cancer such as older age (75%) and having relatives with cancer (70%). A number of ethnic differences were revealed for risk factor beliefs. Black and Hispanic relatives were least likely to correctly identify older age and having relatives with prostate cancer as risk factors for prostate cancer. Further, Black and Hispanic relatives were also most likely to endorse risk factors with no known link to prostate cancer such as stress and sitting on cold surfaces.

Table 6. Distribution of Risk Factor Beliefs.<sup>7</sup>

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	<b>Asian</b> (N=175)	Total (N=1029)
			%	%	%	%	%
Older age	Q59a	Not Yes	20	35	27	19	25
	QJJa	Yes	80	65	73	82	75
Having		Not Yes	19	.38	40	30	31
relatives Q59d with cancer	Yes	81	62.	60	70	69	
Certain	Q59Ъ	Not Yes	65	51	52	57	57
foods	Yes	*35	49	49	43	43	
Stress Q59c	Not Yes	67	59	63	71	65	
	Yes	33	41	37	30	35	
Alcohol 050e	Q59e	Not Yes	82	78	67	76	77
	~~	Yes	18	22	33	24	23
Lack of	Q59f	Not Yes	59	57	52	61	57
exercise	Q371	Yes	41	43	49	39	43
Exposure to	Q59g	Not Yes	45	43	37	43	42
chemicals	QJJg	Yes	55	57	63	57	58
Too much	Q59h	Not Yes	97	96	89	94	94
sex	QJ/II	Yes	3	4	11	6	6
Sitting on		Not Yes	97	88	89	96	93
cold surfaces	Q59i	Yes	3	12	11	5	8
Lack of sex	050:	Not Yes	84	89	82	86	85
	Q59j	Yes	16	11	18	14	15

<sup>7</sup> Shaded areas indicate significant Chi-squared test p < .05.

#### **Cancer-Related Distress**

Overall, the majority of relatives denied experiencing significant cancer-related worry or fear. In the overall sample, 54% of relatives reported they are "not worried", 50% reported they are "not fearful", and 68% reported they are "not nervous" about getting prostate cancer. Alpha coefficients for these items are reported for each ethnicity and across the total sample. Cancer-related distress items were combined to produce a cancer-related distress summary score, that was used in the multivariate prediction of PSA screening status (See page 26).

Table 7. Cancer-Related Distress.8

Question		Response	White	Black	Hispanic	Asian	Total
			(N=354) Alpha=.72	(N=272) Alpha=.78	(N=228) Alpha=.69	(N=175) Alpha=.65	(N=1029) Alpha=.71
How often think about cancer?	Q24	Often	10	21	16	11	14
		Once in a While	69	51	54	53	58
		Never	21	28	30	36	27
How worried about cancer?	Q25	Very Worried	4	6	11	7	7
		Somewhat Worried	41	33	43	39	39
		Not Worried	55	61	46	54	54
How fearful of cancer?	Q26	Fearful	7	11	12	14	11
		Somewhat Fearful	44	34	40	38	40
		Not Fearful	49	55	49	48	50
How nervous about cancer?		Nervous	3	5	5	7	5
	Q27	Somewhat Nervous	26	24	30	32	27
		Not Nervous	71	71	66	61	68
Do you think too often about	625	No	78	82	81	88	81
cancer?	Q28	Yes	22	18	20	12	19

<sup>8</sup> Shaded areas indicate significant Chi-squared test p < .05.

# Perceived Susceptibility to Prostate Cancer

Although all participants were first-degree relatives of prostate cancer patient and thus at elevated risk for getting prostate cancer, a substantial proportion of the sample reported that they are "not likely" to get prostate cancer in their lifetime (26%). Black relatives were most likely to accurately identify Black ethnicity as a risk factor for prostate cancer. White relatives were least likely to rate their likelihood of getting prostate cancer as "not likely."

Table 8. Perceived Susceptibility to Prostate Cancer<sup>9</sup>

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
Who do you		White	6	1	7	9	6
think gets		Black	23	51	12	11	27
prostate	O60	Hispanic	40	0-	12	0	3
cancer		Asian	0	0	0	2	.37
most?		No Difference	70	48	69	78	65
What is the likelihood		Very Likely	19	16	17	12	17
of getting	O61	Somewhat Likely	63	50	58	55	57
		Not Likely	18	35	25	33	26

<sup>9</sup> Chi-squared test p < .05.

#### **Screening Rates**

The majority of our sample had received a DRE at some point during their lifetime (76%) although a minority reported that their most recent DRE was within the last 12 months (41%). A slightly lower percentage of the sample reported having a PSA at some point during their lifetime (56%) and a smaller percentage of those respondents (43%) indicated having their most recent PSA during the last 12 months. A number of ethnic differences emerged for screening variables. White and Black relatives were most likely to report having had a DRE and a PSA. White and Black relatives were most likely to report having had the screening tests during the last year.

Table 9. Screening Behavior by Race. 10

Question		Response	White	Black	Hispanic	Asian	Total
DRE		1980	(N=354)	(N=272)	(N=228)	(N=175)	(N=1029)
			%	%	%	%	%
Have		No	7	11	10	27	12
you ever neard of a DRE?	Q31	Yes	93	89	90	73	88
Have		No	16	22	2.8	36	24
you ever nad a DRE?	Q32	Yes	84	78	72	64	76
When		<1 Year	44	48	31	36	41
was your		≥1 Years	40	30	41	28	35
nost	Q33	Never	-16	23	28	36	24
recent DRE?	per s						
PSA							
Have		No	9	16	35	27-	20
you ever neard of a PSA?	Q34	Yes	91.	84	65	73.	-80
Have		No	40	38	54	46	44
you ever had a PSA?	Q37*	Yes	60	62	45.	54	56
When		<1 Year	43	50	37	42	43
was your	Q39*	1-2 Years	14	7	7	10	10
last	Gaa.	>2 Years	3	5	1	2	3
PSA?		Never	40	38	56	45	44

<sup>10</sup> Shaded areas indicate significant Chi-squared test p < .05.

Table 9. Screening Behavior by Race. 11 (continued)

Sig/Col							
Have you ever		No Yes	9	16 84	21 79	28   72	17 83
heard of Sig/Col?	Q42	1es	31 31	04	19	12	
Have		No	63	63	72	69	66
you ever had a Sig/Col?	Q43	Yes	37	37	38	31	34
When		≤5 Years	38	32	22	27	27
was your		> 5 Years	9	6	6	4	7
most	Q44	Never	63	62	72	69	66
recent							
Sig/Col?							
FOBT							
Have		No	29	25	28	27	31
you ever		Yes	71	75	62	63	69
heard of	Q45						
an FOBT?	7. 7.						
Have		No -	61	57	72	64	63
you ever	Q46	Yes	40	43	28	36	37
taken an FOBT?							
When	22270 200 12	< 1 Year	15	17	11	14	15
was your		1-2 Years	7	7	7	9	8
most	Q47	>2 Years	16	18	11	13	15
recent FOBT?		Never	61	58	72	64	63

<sup>11</sup> Shaded areas indicate significant Chi-squared test p < .05.

## Predicting PSA Receipt (Bivariate predictors)

## Demographic Variables as Bivariate Predictors of Lifetime Receipt of PSA

Overall, among demographic variables, age was the only factor predictive of lifetime receipt of a PSA test across the total sample as well as within each ethnic group. Analyses indicated that relatives over the age of 60 were significantly more likely to have had a PSA than relatives under the age of 60. Across the total sample, having a college education or higher predicted an increased likelihood of PSA receipt as compared to relatives with lower levels of education however this relationship was not significant within ethnic groups. Income level similarly was predictive of an increased likelihood of PSA receipt among the total sample in that higher income levels were associated with increased likelihood of PSA receipt however the effect was only observed for the total sample and for Black relatives. Marital status was also predictive of increased likelihood of PSA receipt among all relatives with married relatives being more likely to have received a PSA than unmarried relatives. Being born in the USA was also a significant predictor of increased likelihood of PSA receipt as compared to relatives that were immigrants to the U.S. across the total sample.

Table 11. Percentage of Men Who Have Had a PSA, Given Demographic Characteristics of Baseline Respondents. 12

Variable	White (N=354)	Black (N=272)	Hispanics (N=228)	Asian (N=175)	Total (N=1029)
Age*	%	%	%	%	%
Age < 60	51	48	31	45	45
Age ≥ 60	78	79	73	65	75
Education				- 41	
High school and above	54	54	39	38	48
College and above	58	60	42	52	54
Incomes*					
Below \$55K	55	49	38	42	46
\$55K and above	58	66	41	54	56
Marriage					
Yes	61	62	43	51	55
No	42	43	30	46	
Born in U.S.					
Yes	57	57	43	49	54
No	48	80	38	52	46

<sup>12</sup> Shaded areas indicate significant two sample Z test for proportions, total and by race, p < .05.

# Demographic Variables as Bivariate Predictors of Receipt of PSA within last 12 Months

Fewer significant predictors were found for the outcome of receipt of PSA in the last 12 months. Only age and marital status emerged as significant predictors of receipt of a PSA test during the last 12 months with older and married relatives having an increased likelihood of being screened during the last 12 months as compared to their younger and un-married counterparts.

Table 12. Percentage of Men Who Have Had a PSA within the Last 12 Months, Given

Demographic Characteristics of Baseline Respondents. 13

Variable	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
Age*	%	%	%	%	%
Age < 60	32	40	23	33	32
Age ≥ 60	65	58	64	48	61
Education					
High school and below	42	40	31	31	37
College and above	40	49	34	40	41
Incomes*					
Below \$55K	44	38	31	35	37
\$55K and above	40	54	32	40	42
Marriage					
Yes	44	49	36	41	-43
No	28	33	22	31	28
Born in USA					
Yes	41	45	35	38	41
No	38	60	29	40	36

<sup>13</sup> Shaded areas indicate significant two sample Z test for proportions, total and by race, p < .05.

#### Knowledge of Screening Guidelines as Bivariate Predictor

Level of knowledge in regards to screening guidelines was a significant predictor of receipt of a PSA ever and receipt of a PSA within the last 12 months. Belief that PSA screening should begin at an early age and should occur frequently (i.e., every 6 month) was predictive of higher rates of lifetime PSA screening and receipt of PSA during the last 12 months as compared to beliefs that screening should start at later ages and should occur less frequently.

Table 13. Percentage of Men Who Have Had a PSA, Given Screening Guidelines Knowledge.

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
	_		%	%	%	%	%
At what age should he have his	Q86	30 40 50 60	63   56   59   20	56 60 58 25	38 45 26 17	76 49 40 45	56 53 48 29
first PSA? How often should a		Every 6 m Yearly	64	82 58	50 44	75 57	71 55
man such as yourself have a PSA?	Q87	2-3 Years > 3 Years	49 27	41 43	18	26	27

Table 13a. Percentage of Men Who Have Had a PSA within 12 Months, Given Guideline Screening Knowledge.

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
			%	%	%	%	%
At what age		30	43	43	31	52	42
should he have his	Q86	40	39	47	36	36	40
		50	45	45	24	38	40
first PSA?		60	10	25	17	45	26
How often		Every 6 m	55	68	42	75	62
should a		Yearly	44	47	35	43	43
man such as	00-	2-3 Years	32	21	21	19	25
yourself have a PSA?	Q87	>3 Years	9	29	9	0	12

# Risk Factors Beliefs as Bivariate Predictor

Overall, risk factors beliefs were poor predictors of PSA screening status with only two factors emerging as significant predictors of only one PSA outcome, receipt of PSA ever. Specifically, relatives who cited certain foods and exposure to chemicals as risk factors for prostate cancer were less likely to ever have had a PSA test than were relatives who did not identify diet and chemical exposure as risk factors. No risk factors predicted receipt of a PSA during the last 12 months.

Table 14. Percentage of Men Who Have Had a PSA, Given Risk Factor Beliefs. 14

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	<b>Asian</b> (N=175)	<b>Total</b> (N=1029)
			%	%	%	%	%
Older age	Q59a	Not Yes	51	54	33	53	48
_	QJ9a	Yes	58	59	44	50	54
Certain	Q59b	Not Yes	60	60	41	55	55
foods	Q390	Yes	51	55	40	45	49
Stress	Q59c	Not Yes	60	57	39	53	54
	Q39C	Yes	50	58	43	45	50
Having		Not Yes	62	54	49	46	53
relatives Q59 with cancer	Q59d	Yes	56	60	35	63	52
Alcohol	Q59e	Not Yes	57	58	40	54	53
	Q370	Yes	56	56	42	42	49
Lack of	Q59f	Not Yes	61	55	41	52	54
exercise	Q391	Yes	50	62	40	49	51
Exposure to	Q59g	Not Yes	61	60	44	54	56
chemicals	QJJg	Yes	53	56	39	48	50
Too much	Q59h	Not Yes	57	58	40	40	52
sex	QJJII	Yes	60	58	42	60	52
Sitting on		Not Yes	57	58	43	50	53
cold surfaces	Q59i	Yes	58	58	20	75	47
Lack of sex	Q59j	Not Yes	58	58	42	50	53
	(23)	Yes	50	58	35	58	50

<sup>14</sup> Shaded areas indicate significant two sample Z test for proportions, total only p < .05.

Table 14a Percentage of Men Who Have Had a PSA within 12 Months, Given Risk Factor Beliefs. 15

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	<b>Asian</b> (N=175)	Total (N=1029)
	,		%	%	%	%	%
Older age	Q59a	Not Yes	32	47	25	44	37
	QJJa	Yes	42	45	36	38	41
Certain	Q59b	Not Yes	43	48	32	43	42
foods	Q390	Yes	35	42	33	35	37
Stress	Q59c	Not Yes	44	47	30	43	41
	QJJC	Yes	32	44	37	32	37
Having		Not Yes	44	44	39	37	41
relatives Q59d with cancer	Yes	40	46	28	41	39	
Alcohol	Q59e	Not Yes	41	45	32	42	41
	QJJC	Yes	37	47	24	30	38
Lack of	Q59f	Not Yes	44	44	34	42	42
exercise	QJJ1	Yes	35	47	31	36	38
Exposure to	Q59g	Not Yes	43	49	35	43	43
chemicals	Qoyg	Yes	39	43	31	36	37
Too much	Q59h	Not Yes	40	46	33	38	40
sex	QJJII	Yes	60	33	31	60	41
Sitting on		Not Yes	40	46	35	39	40
cold surfaces	Q59i	Yes	50	42	16	50	36
Lack of sex	Q59j	Not Yes	41	46	34	38	40
	[ G23]	Yes	38	39	25	46	36

<sup>15</sup> Shaded areas indicate significant two sample Z test for proportions, total only p < .05.

#### Cancer-related Distress as Bivariate Predictor

Psychometric analysis of items assessing cancer-related distress indicated that these items could be combined to compute a cancer-related stress summary score. The composite cancer-related distress score did not predict PSA receipt ever or during the past 12 months and was very similar for men of all ethnic groups.

Table 15 Average Cancer-Related Distress Score and Relationship to PSA Receipt in the Past 12 Months. 16

Variable	White	Black	Hispanics	Asian	Total
No PSA < 12 Mo.	1.72	1.77	1.83	1.78	1.74
PSA < 12 Mo.	1.78	1.76	1.79	1.81	1.75

#### **Multivariate Prediction of PSA Screening Status**

Logistic regression analysis was performed for the total sample and for the four ethnic subgroups with receipt of PSA during the last 12 months as the outcome. In all models predictor variables included age, marital status (married vs. not married), education, health insurance, sum of barriers score. Country of birth (born in U.S. vs. born out of U.S.) was added for Hispanic and Asian subgroup analyses. Bivariate analyses detected consistent significant relationships between income and other demographic predictor variables, therefore all logistic regression analyses were performed controlling for income by entering income prior to all other predictor variables. As indicated in Table 17 below, for the total sample, age, marital status, insurance, and barriers emerged as significant predictor variables. That is, older married participants with health insurance who endorsed fewer barriers to screening were more likely to have received a PSA test during the last 12 months. For White relatives, only age and barriers emerged as significant predictors such that older participants reporting fewer barriers to screening were more likely to have received a PSA test during the last year. Among Black and Hispanic participants, age, barriers, and insurance were significant predictors. Regression analyses performed within the Asian sample found age and insurance to be the only significant predictors of PSA receipt during the last 12 months. Furthermore, among Asian relatives no relatives who received screening were uninsured therefore multivariate prediction of screening by insurance was not possible.

Table 17. Logistic Regression Analyses: Predicting PSA Receipt in past 12 months

Predictor	ł	<b>-</b> 1		White   Black (N=272)			Hispanic (N=228)		<b>Asian</b> (N=175)	
	OR	CI	OR	CI	OR	CI	OR	CI	OR	CI
Age	3.45*	2.47-4.82	4.00*	2.26-7.10	2.14*	1.16-3.98	6.72*	2.88-15.69	4.20*	1.76-10.01
Married	1.48*	1.03-2.13	1.81	.95-3.43	1.37	.71-2.66	1.80	.76-4.23	1.13	.43-2.95
Education	1.01	.97-1.06	1.01	.93-1.10	1.08	.98-1.18	.95	.86-1.05	1.10	.96-1.27
Insured	3.33*	1.75-6.31	2.33	.70-7.74	3.14*	1.07-9.22	4.56*	1.29-16.16	N/A	N/A
Barriers	.65*	.5676	.52*	.3970	.71*	.5395	.59*	.4186	.77	.56-1.07
US Born	-	-	-	-	-	-	1.15	.56-2.33	.69	.34-1.39

<sup>16</sup> Shaded areas indicate significant two sample t-test, total and by race, p < .05.

#### Attitudes about Participation in Clinical Trials

Overall, a very low percentage of all relatives (5%) reported any history of participation in a clinical trial and no significant differences were observed across ethnicity. Approximately 37% of the overall sample reported they would participate in the Prostate Cancer Prevention (PCPT) Trial, 55% in the Prostate, Lung, Colorectal, and Ovarian Cancer Screening (PLCO) trial, and 55% in the Selenium and Vitamin E Cancer Prevention (SELECT) Trial. Black and Hispanic relatives were most likely to report that they would participate in PCPT and PLCO trials. All ethnic groups appeared equally willing to participate in the SELECT trial. Concern with experiencing side effects was the most commonly cited reason for not participating in a clinical trial with 68% of the sample endorsing this reason. Other major concerns were "having to take a pill daily" (41%), the length of the trial (38%), and having to get a biopsy (33%). Men were less concerned about blood tests, a rectal exam, and completion of questionnaires.

Table 16. Willingness to Participate in Particular Clinical Trials<sup>17</sup>

Question		Response	White	Black	Hispanic	Asian	Total
Have you		No	94	95	96	97	95
participated in a clinical trial?	Q92	Yes	6	5	4	3	5
PCPT Study							
Would you	Q95	Not Yes	67	59	56	69	63
participate?	Q90	Yes	33	41	44	31	37
Which are reas	ons not to p	articipate?	· · · · · · · · · · · · · · · · · · ·				
Take a pill	Q96a	Not Yes	63	58	60	50	59
daily	Q20a	Yes	37	42	40	50	41
Possible	Q96b	Not Yes	31	33	31	30	32
side effects	Q900	Yes	68	67	69	70	68
Having to	Q96c	Not Yes	65	69	71	62	67
get biopsy	Q30C	Yes	35	31	29	38	33

<sup>17</sup> Chi-squared test p < .05.

Table 16 (continued) Willingness to Participate in Particular Clinical Trials

PLCO Study							
Would you participate?	Q97	Not Yes Yes	60 50	40 60	39 60	47 53	45 55
Which are reason	s not to par	rticipate?		•			
Having to get blood test	Q98a	Not Yes Yes	96 4	97	93	95 5	95 5
Having to get rectal exam	Q98b	Not Yes Yes	86 14	85 15	96 14	89 11	86 14
Having to fill out questionnaires	Q98c	Not Yes Yes	90	91	12	90	90
Vitamin E							
Would you participate?	Q99	Not Yes Yes	42 58	45 55	43 56	53 57	45 55
Which are reason	s not to pa	rticipate?					
Having to take vitamins	Q100a	Not Yes Yes	88	89 11	85 -15	81 19	86 14
The length of the trial	Q100Ъ	Not Yes Yes	63	68 32	63 37	50 50	62

Represented below in Table 17 are reported barriers to participation in clinical trials, that were assessed in a series of closed-ended questions. In the total sample, the most frequently endorsed barriers were "never thought about participating", "doctor never recommended participating", and fear of being a guinea pig.

Table 17. General Reasons Not to Participate in Clinical Trials. 18

Question		Response	White	Black	Hispanic	Asian	Total
Afraid of being a guinea pig	Q101a	Not Yes Yes		65   35	37	40	34
Afraid will get cancer as a result	Q101b	Not Yes Yes	89 11	<b>82</b>   <b>18</b>	23	74 26	82 18
Fear of becoming impotent	Q101c	Not Yes Yes	93	81 19	77 23	76 23	<b>84</b>   <b>16</b>
Never thought about participating	Q101d	Not Yes Yes	52 48	56 44	52 48	51 49	53 47
Doctor never recommended participating	Q101e	Not Yes Yes	46	70 - 31	52 48	40	59 41
It is associated with homosexuality	Q101f	Not Yes Yes	99	96	95.	95	97
Too uncomfortable or painful	Q101g	Not Yes Yes	84 16	23	71 29	27	78 22

<sup>18</sup> Shaded areas indicate significant Chi-squared test p < .05.

A substantial number of respondents also endorsed positive attitudes towards clinical trials. Most relatives (89%) believed that they may learn something by participating in a clinical trial that will benefit their health. Less than half (45%) believed that participation would prolong their lives. There was more uncertainty about benefits regarding prolonged life than about the educational benefits, as reflected in the "no opinion/don't know" category.

Table 18. Beliefs and Attitudes about Clinical Trials. 19

Question		Response	White	Black	Hispanic	Asian	Total
Participating in clinical trials will prolong my life.	Q103	Disagree	37	30	23	32	31
		No Opinion / DK	27	26	21	20	24
		Agree	36	44	56	48	45
I may learn something that will benefit my health.	Q104	Disagree	5	4	2	5	4
		No Opinion / DK	6	8	7	5	6

#### Validation Analyses

We assessed the validity of self-reported PSA receipt by calculating the percent agreement between self-report and physician report of PSA receipt for both PSA during the last 12 months and lifetime receipt of PSA. The percent agreement between self-report and physician report of lifetime receipt of PSA was high. Physician report of lifetime PSA receipt was verified for 151 of the 178 relatives who reported receiving a PSA at sometime during their life resulting in 85% agreement. However, the percent agreement for receipt of PSA during the last 12 months was lower. Self-report of PSA receipt during the last 12 months was verified by physician report for 83 of the 144 relatives who self-reported PSA receipt in the last 12 months resulting in a 58% agreement. The lowered agreement between self-report and physician report for PSA receipt during the last 12 months may be due to inaccurate subject recall of the timing of the test. Previous research has found that medical patients tend to underestimate the time interval since their last cancer screening procedure.

<sup>19</sup> Shaded areas indicate significant Chi-squared test p < .05.

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#### **CONCLUSION**

Our recruitment method was successful in obtaining an ethnically diverse population-based sample of first-degree relatives of prostate cancer cases. We obtained contact information for first-degree relatives by requesting the information from consenting prostate cancer cases listed through the California Cancer Registry. Among cases and relatives that could be contacted, refusal rates were reasonable. The higher refusal rate among cases (35%) as compared to relatives (10%) probably occurred because many cases felt uncomfortable giving out personal information about their relatives. Relatives, however, aware that the case was participating in our study, were less likely to refuse participation. Through our recruitment efforts, we were able to recruit relatively large samples of White, Asian, African-American, and Hispanic first-degree relatives. However, there were a large percentage of cases and relatives who could not be reached due to incorrect addresses, discontinued telephone numbers, etc., thus compromising the representativeness of the sample and generalizability of findings.

Through our survey, we obtained a substantial amount of information about our sample including demographic information, knowledge of prostate cancer screening, reported barriers to PSA testing, prevalence of cancer-related distress and prostate cancer screening rates. Overall, the majority of the sample was married, over the age of 60, with at least some college education and an income of \$55,000 or higher. Further, the vast majority of our sample reported having some type of health insurance. Most did not endorse many barriers to screening such as cost. problems with transportation to the clinic, or fear that a screening test would find cancer. Most relatives believed that due to their higher risk status, as first-degree relatives, that they should begin to have a yearly PSA test beginning at the age of 40. Most relatives were aware of the known risk factors for prostate cancer including older age and having relatives with prostate cancer; however, the majority of relatives also inaccurately believed that exposure to chemicals may increase their risk for prostate cancer. The majority of our sample reported no significant cancer-related distress. The vast majority of relatives reported having a DRE sometime in their life (76%) however less than half had a DRE during the last 12 months. Rates were lower for PSA receipt with only 56% of the sample reporting having a PSA sometime during their lifetime and only 43% having a PSA test during the last 12 months.

We also examined bivariate predictors of both lifetime receipt of a PSA and receipt of a PSA test during the last 12 months. Age (60 years or older), income (\$55,000 or over), being born in the US, and being married were bivariately predictive of higher rates of lifetime PSA receipt. Higher rates of lifetime receipt of PSA were also found among men who believed that PSA testing should start at earlier ages (i.e., 30 years) and should occur more frequently (i.e., every 6 months) as compared to men who believed that PSA testing should start at later ages and less frequently. Men who were less informed about risk factors for prostate cancer had lower lifetime rates of screening than men who were more knowledgeable about risk factors. Similar bivariate relationships detected for prediction of PSA testing during the last 12 months although fewer significant relationships were found.

Finally, we conducted logistic regression analyses to predict receipt of PSA testing during the last 12 months. Due to bivariate relationships detected between income and other demographic predictors, all logistic analyses were performed controlling for income. Analyses revealed that older married participant with health insurance who endorsed fewer barriers to screening were more likely to have received a PSA test during the last 12 months as compared to

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other participants. This suggests that barriers counseling might be a successful strategy to increase PSA screening.

We also assessed attitudes about and participation in clinical prevention trials. A low proportion of the sample (5%) reported ever participating in a prevention or screening trial. The majority of participants indicated that they would be willing to participate in two out of three prostate cancer prevention trials that were described in detail. The most common reasons reported for not participating in a prevention trial was not receiving a doctor recommendation to participate and not having thought about participation in the past. Other reasons reported less frequently included fear of being a guinea pig, fear that participation might be painful or uncomfortable, and fear of getting cancer because of participation. This underscores the important role that physicians play in clinical trials recruitment.

Overall, we were able to recruit a large and diverse sample of first-degree relatives of prostate cancer cases and gain a better understanding of their knowledge, attitudes, and behaviors in regards to prostate cancer screening. We also assessed their level of distress in regards to their risk status and assessed their attitudes towards and participation in prevention and screening clinical trials.

RE	$\mathbf{F}\mathbf{F}$	R	$\mathbf{E}$	N	$\mathbf{CE}$	S

N/A

**BIBLIOGRAPHY** 

N/A

#### LIST OF PERSONNEL

**BASTANI, ROSHAN** BEDDO, VANESSA C DURAN, MICHELLE **EVERETT, JAMAAR PRINCE GINZBURG, DMITRIY** GARCIA-HESKETT, CONNIE KAWAMOTO, KRISTAL C LIM, MICHELLE P LITWIN, MARK MAXWELL, ANNETTE E MOJICA, CYNTHIA M PLATERO, JUAN C. QUEVEDO JR,RAYMOND H RAWAF, MUSTAFA MOAIUD RIOS, FATIMA LOURDES RUNAS, FRANCIS MATTHEW SCHROEDER, JUSTINE ELISABETH SWANSON,KAREN A WALDEN, THOMAS EUGENE WARDA, UMME SHEFA YAN, KANGXIONG ZAMORA, ERIC ZHUANG, JEFF ZU LIANG

#### **APPENDICES (SEE ATTACHED)**

- 1. Final version of questionnaire (English & Spanish versions)
- 2. Case and relative recruitment materials (Two case & two relative samples included)
- 3. Mailed questionnaire
- 4. Letter to relative requesting permission to verify receipt of tests (English, Spanish)
- 5. Letter to subjects who verbally agreed to validation during survey(English, Spanish)
- 6. Verification form (English, Spanish)
- 7. Letter to providers requesting validation of self-report

Appendix 1: Final Version of Questionnaire (English & Spanish translation)

Scenario # ( (568)

#### INTRODUCTION/VERBAL CONSENT

NOTE FOR 1st PARAGRAPH:

\*IF RID = "2" CHOOSE SON, IF RID = "4" CHOOSE BROTHER, IF RID = "6" CHOOSE FATHER.

\*INSERT PTFNAME AND PTLNAME IN SECOND BLANK

Hello, my name is	and I am calling from the	UCLA Cancer Center. Your
[BROTHER, FATHER, SON]	gave us your name.	Did he talk to you about this
study?		

- 1 YES → Good. Let me remind you...
- 0 NO → Let me explain that...

We are doing telephone interviews with close relatives of men who have had prostate cancer. The interview will take about 20 minutes and asks your opinion and belief about cancer, your health practices and some background information about you. Your answers will help us develop programs to educate people about early detection of prostate cancer.

We recently sent you some materials explaining the study. Did you receive it?

Let me assure you that all your answers will be confidential. All information will be used only for the purposes of this study. No information which identifies you will be released without your consent. Your participation is completely voluntary and you can stop the interview at any time.

If you would like, I can give you the telephone number for Dr. Bastani, who is conducting this project, so that you can contact her if you have any questions now or in the future. [DR. BASTANI'S NUMBER IS: 310.206.9266; RESPONDENTS MAY CALL COLLECT]

I can also give you the Vice Chancellor's [310.825.8714] and the Human Subjects Protection Committee number [310.825.7122] at UCLA.

\*\*\*\*

NOTE: FOR Q0A, IF ANSWER IS "NO" SURVEY WILL BE TERMINATED. ENTER CODE "7" FOR SRVSTAT1 AND CODE "3" TO SRVTERM1 IN RELATIVE TRACKING DATABASE
\*\*\*\*\*

Q0A Would you be willing to answer some questions?

- 1 YES → CONTINUE
- 0 NO →I understand your decision. If you do have questions about prostate cancer, early detection and treatment, you can call the Cancer Information Service. Would you like their toll free number? (1-800-4-CANCER). If you change your mind about participating, please feel free to call us toll-free at 1-877-278-8506. Thank you for your time. Good bye. **GO TO SUMMARY SCREEN.**

Q0B Is this a good time for you?

1 YES → CONTINUE

0 NO → When may I call you again? \_\_\_\_\_ GO TO LOGSHEET

Let me assure you that there is **no** right or wrong answer. We are interested only in finding out what **you** feel and what **you** believe about cancer and other issues.

1 \	•	W. DK X. RF
only wit		o participate at this time. Unfortunately, the telephone survey is conducted 75 years of age. Do you have any questions for me before we end this call?
IN SRV	TERM1]	TER '0' VARIABLE "RELIG2" ALSO ENTER "7" IN SRVSTAT1 AND "7"
Q004.	I'd like to ask you some ques	tions about your health.
Has a	doctor ever told you that you hav	ve or had any type of cancer?
1 ` 0	YES NO (GO TO → Q007)	W. DK (GO TO → Q007) X. RF (GO TO → Q007)
CALL.		:= '2', SUBJECT IS INELIGIBLE FOR STUDY. GO TO Q0006 AND END TRACKING DATABASE VARIABLE RELIG2 = "2", SRVSTAT1 = "7",
GO TO	SUMMARY SHEET BEFORE	RETURNING TO LOG SHEET
Q005.	What type of cancer? Q005a _	, Q005b, Q005c
	<ol> <li>Colon (GO TO -&gt; Q007)</li> <li>Prostate</li> <li>Lung (GO TO -&gt; Q007)</li> </ol>	
	V. Other	(Q005S) (GO TO -> Q007)
	"I'm sorry to hear that. I appred is conducted only with those whis call? Thank you for your time	ciate your willingness to participate in this study. Unfortunately, the telephone o have not had prostate cancer. Do you have any questions for me before we . Good-bye."
Q007.	In general, would you say you	health is
2. 3. 4.	Excellent Very good W. D Good X. R Fair Poor	

Q001. Let me begin by verifying that you are between the ages of 40 and 75. Is that correct?

Q008.		ver told you that you hat you have got the second to be seen to be seen that you will be seen to be seen to be		rged or	swollen prostate? T	his is also known	as
	YES NO						
*****	· ******						
	DELETED						
*****			•				
* IF RI	RT PTFNAME IN				ER; IF RID = "6" C} ASKING Q010, SKI		
Q010.	Now I'd like to	ask you some qu	uestions about	your fa	amily and <u>their</u> hea	lth.	
Let's s diagno	tart with your [FA	THER, BROTHER cancer, has he b	R, SON] een diagnosed v	with any	who gave us other type of cance	your name. Asid	e from being
	1. YES 0 NO (GO TO	) → Q011)	W. DK X RF	(GO T	ΓO → Q011) O → Q011)		
What	type of cancer?	At what age was	he diagnosed?				
(Q010 (Q010	a1) )a2)	(Q010b1) (Q010b2)					
	<ol> <li>Colon</li> <li>Prostate</li> <li>Breast</li> <li>Lung</li> </ol>						
	V. Other W. DK X. RF						
Q011.	Now I'll read yo	u a list of your oth	er relatives. Ple	ease tel	I me if any of them	have had any typ	e of cancer?
Your <b>f</b>	ather?						
	YES NO (GO TO -		W. DK (GO TO X RF (GO TO				·
What	type of cancer?	At what age was	he diagnosed?		Is your father(1) on (2) your stepfat		"blood"
(Q011 (Q01	a1) 1a2)	(Q011b1) (Q011b2)	<u>-</u>		(Q011c)_		
	<ol> <li>Colon</li> <li>Prostate</li> <li>Breast</li> <li>Lung</li> </ol>				W. DK X. RF		
	V. Other						

W.	DK
X.	RF

Q012. Your mother?		
1 YES 0 NO ( <b>GO TO →</b>		O TO → Q013) TO → Q013)
What type of cancer?	At what age was she diagnosed?	is your mother (1) related to you by "blood" OR (2) your stepmother?
(Q012a1) (Q012a2)	(Q012b1) (Q012b2)	(Q012c)
<ol> <li>Colon</li> <li>Breast</li> <li>Cervical</li> <li>Lung</li> <li>Ovarian</li> <li>Endometrian</li> </ol>	al	W. DK X. RF
V. Other W. DK X. RF	•	
**************************************	CORRESPONDING NUMBER OF B	ROTHER SECTIONS INDICATED IN Q013a
		ME, HAVE ANY OF YOUR OTHER BROTHERS BEEN
0. NO (GO TO - W. DK (GO TO	nany?(Q013a) → Q014)	
X. RF (GO TO -	→ Q014)	
	At what age was he diagnosed?	
(Q013_1aTyp) (Q013_1bTyp)	(Q013_1aAge) (Q013_1bAge)	

```
1 MOTHER
2 FATHER
W DK
X RF
```

Colon
 Prostate
 Breast
 Lung

V. Other W. DK X. RF

Q013\_1c. Is your brother...

1 MOTHER 2 FATHER

W DK X RF

**BROTHER 2:** 

(Q013\_2aTyp) \_

(Q013\_2bTyp)\_

Colon
 Prostate
 Breast
 Lung

V. Other W. DK X. RF

Q013\_2c Is your brother...

W DK X RF

2 your half brother

2 your half brother

1 related to you by "blood" (GO TO ->BRO 2, (IF ANY), SISTER Q014)

3 your step brother (GO TO -> BRO 2, (IF ANY), SISTER Q014)

(Q013\_2aAge)\_\_

(Q013\_2bAge)\_\_\_

1 related to you by "blood" (GO TO ->BRO 2, ( IF ANY), or SISTER Q014 )

(GO TO ->BRO 2, (IF ANY), SISTER Q014)

(GO TO -> BRO 2, (IF ANY), SISTER Q014)

3 your step brother (GO TO -> BRO 2, (IF ANY), SISTER Q014)

Q013\_2d Is your half brother from your mother's or father's side?

W. DK (GO TO ->BRO 2, (IF ANY), SISTER Q014)
X. RF (GO TO ->BRO 2, (IF ANY), SISTER Q014)

Q013 1d Is your half brother from your mother's or father's side?

What type of cancer? At what age was he diagnosed?

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BROTHER 3:	
What type of cancer?	At what age was he diagnosed?
(Q013_3aTyp) (Q013_3bTyp)	(Q013_3aAge) _ (Q013_3bAge)
<ol> <li>Colon</li> <li>Prostate</li> <li>Breast</li> <li>Lung</li> </ol>	
V. Other W. DK X. RF	
Q013_3c Is your broth	er
2 your half brot	by "blood" (GO TO ->BRO 3, (IF ANY), SISTER Q014) her ther (GO TO ->BRO 3, (IF ANY), SISTER Q014)
W. DK (GO TO X. RK (GO TO	D ->BRO 3, (IF ANY), SISTER Q014) D ->BRO 3, (IF ANY), SISTER Q014)
Q013_3d Is your half	brother from your mother's or father's side?
1 MOTHER 2 FATHER	
W DK X RF	
**************************************	CORRESPONDING NUMBER OF SISTER SECTIONS INDICATED IN Q014a
1. YES -> How m 0. NO (GO TO →	any?(Q014a) Q015)
W. DK (GO TO - X. RF (GO TO -	•
SISTER 1:	
What type of cancer?	At what age was she diagnosed?
(Q014_1aTyp) (Q014_ 1bTyp)	
<ol> <li>Colon</li> <li>Breast</li> </ol>	

4. Cervical 5. Lung 6. Ovarian 7. Endometrial V. Other W. DK X. RF Q014\_1c Is your sister... 1 related to you by "blood" (GO TO ->SISTER 2, (IF ANY), SON Q015) 2 your half sister 3 your step sister (GO TO ->SISTER 2, (IF ANY), SON Q015) (GO TO ->SISTER 2, (IF ANY), SON Q015) W. DK X. RF (GO TO ->SISTER 2, (IF ANY), SON Q015) Q014\_1d Is your half sister from your mother's or father's side? 1 MOTHER 2 FATHER W DK X RF SISTER 2: What type of cancer? At what age was she diagnosed? (Q014\_2aTyp)\_ (Q014\_2aAge)\_ (Q014\_2bAge)\_\_\_ (Q014\_2bTyp)\_\_ 1. Colon 3. Breast 4. Cervical 5. Lung 6. Ovarian 7. Endometrial V. Other W. DK X. RF Q014\_2c Is your sister... 1 related to you by "blood" (GO TO ->SISTER 3 (IF ANY)OR SON Q015) 2 your half sister 3 your step sister (GO TO ->SISTER 3 (IF ANY)OR SON Q015)

Q014\_2d Is your half sister from your mother's or father's side?

W DK X RF

2 FATHER
W DK X RF
SISTER 3:
What type of cancer? At what age was she diagnosed?
(Q014_3aTyp) (Q014_3aAge) (Q014_3bTyp) (Q014_3bAge)
<ol> <li>Colon</li> <li>Breast</li> <li>Cervical</li> <li>Lung</li> <li>Ovarian</li> <li>Endometrial</li> </ol>
V. Other W. DK X. RF
Q014_3c Is your sister
1 related to you by "blood" (GO TO ->Q015) 2 your half sister 3 your step sister (GO TO ->Q015)
W. DK X. RF
Q014_3d Is your half sister from your mother's or father's side?
1 MOTHER 2 FATHER
W DK X RF
**************************************
IF A SON WAS THE "CASE" PHRASE Q015 AS:
"ASIDE FROM THE SON WHO GAVE US YOUR NAME, HAVE ANY OF YOUR OTHER SONS BEEN DIAGNOSED WITH CANCER?"
Q015. Have any of your sons been diagnosed with cancer?
1. YES -> How many?(Q015a)

### W. DK (GO TO → Q016) X. RF (GO TO → Q016)

0. NO (GO TO → Q016)

#### **SON 1:**

What type of cancer? At what age was he diagnosed?

(Q015\_1aTyp) \_\_\_\_\_ (Q015\_1aAge)\_\_\_ (Q015\_1bTyp) \_\_\_\_ (Q015\_1bAge)\_\_\_

- 1. Colon
- 2. Prostate
- 3. Breast
- 5. Lung
- V. Other
- W. DK
- X. RF

Q015\_1c is your son...

- 1 related to you by "blood" (GO TO ->SON 2 (IF ANY)OR DAUGHTER Q016)
- 2 your adopted son (GO TO ->SON 2 (IF ANY)OR DAUGHTER Q016)
- 3 your step son (GO TO -> SON 2 (IF ANY)OR DAUGHTER Q016)
- W. DK (GO TO ->SON 3 (IF ANY)OR DAUGHTER Q016)
- X. RF (GO TO -->SON 3 (IF ANY)OR DAUGHTER Q016)

#### SON 2:

What type of cancer? At what age was he diagnosed?

(Q015\_2aTyp) \_\_\_\_\_ (Q015\_2aAge)\_\_\_ (Q015\_2bTyp)\_\_\_\_ (Q015\_2bAge)\_\_\_\_

- 1. Colon
- 2. Prostate
- 3. Breast
- 5. Lung
- V. Other
- W. DK
- X. RF

Q015 2c Is your son...

- 1 related to you by "blood" (GO TO ->SON 3 (IF ANY) OR DAUGHTER Q016)
- 2 your adopted son (GO TO ->SON 3 (IF ANY) OR DAUGHTER Q016)
- 3 your step son (GO TO ->SON 3 (IF ANY) OR DAUGHTER Q016)
- W. DK (GO TO ->SON 3 (IF ANY) OR DAUGHTER Q016)
- X. RF (GO TO ->SON 3 (IF ANY) OR DAUGHTER Q016)

#### **SON 3:**

What type of cancer? At what age was he diagnosed?

(Q015_3aTyp) (Q015_3bTyp)	(Q015_3aAge) (Q015_3bAge)
<ol> <li>Colon</li> <li>Prostate</li> <li>Breast</li> <li>Lung</li> </ol>	
V. Other W. DK X. RF	
Q015_3c is your son	•
1 related to you by "bloo 2 your adopted son 3 your step son	od"
W. DK X. RF	
****	
NOTE FOR Q016: ONLY DISPLAY THE CORRES	SPONDING NUMBER OF DAUGHTER SECTIONS INDICATED IN Q016a
Q016. Any of your daughters?	<b>}</b>
<ol> <li>YES -&gt; How many?</li> <li>NO (GO TO → Q017)</li> </ol>	(Q016a)
W. DK (GO TO → Q017) X. RF (GO TO → Q017)	
DAUGHTER 1:	
What type of cancer? At wha	t age was she diagnosed?
(Q016_1aTyp) (Q016_1bTyp)	(Q016_1aAge) (Q016_1bAge)
<ol> <li>Colon</li> <li>Breast</li> <li>Cervical</li> <li>Lung</li> <li>Ovarian</li> <li>Endometrial</li> </ol>	
V. Other W. DK X. RF	
Q016_1c Is your daughter	

1 related to you by "blood" (GO TO -> DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017)

2 your adopted daughter (GO TO -> DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017) 3 your step daughter (GO TO -> DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017)

W. DK (GO TO -> DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017) X. RF (GO TO -> DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017)

#### **DAUGHTER 2:**

What type of cancer?	At what age was she diagnosed?
vvnat type of cancer?	At what ade was she diadhosed?

(Q016\_2aAge)\_ (Q016\_2aTyp) \_\_\_\_\_ (Q016\_2bAge)\_\_\_ (Q016\_2bTyp)\_\_\_\_

- 1. Colon
- 3. Breast
- 4. Cervical
- 5. Lung
- 6. Ovarian
- 7. Endometrial
- V. Other
- W. DK
- X. RF

#### Q016\_2c Is your daughter...

- 1 related to you by "blood" (GO TO ->DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)
- 2 your adopted daughter (GO TO -> DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)
- 3 your step daughter (GO TO -> DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)

W. DK (GO TO -> DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)

X. RF (GO TO -> DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)

#### **DAUGHTER 3:**

What type of cancer? At what age was she diagnosed?

(Q016\_3aTyp) \_\_ (Q016\_3aAge)\_ (Q016\_3bAge)\_\_\_ (Q016\_3bTyp)\_\_\_

- 1. Colon
- 3. Breast
- 4. Cervical
- 5. Luna
- 6. Ovarian
- 7. Endometrial
- V. Other
- W. DK
- X. RF

#### Q016\_3c is your daughter...

- 1 related to you by "blood"
- 2 your adopted daughter
- 3 your step daughter
- W. DK
- X. RF

**************************************
ONLY DISPLAY THE CORRESPONDING NUMBER OF GRANDFATHER SECTIONS
Q017. Any of your grandfathers?
<ol> <li>YES -&gt; How many?(Q017a)</li> <li>NO (GO TO → Q018)</li> </ol>
W. DK (GO TO → Q018) X. RF (GO TO → Q018)
GRANDFATHER 1:
What type of cancer? At what age was he diagnosed?
(Q017_1aTyp) (Q017_1aAge) (Q017_1bTyp) (Q017_1bAge)
<ol> <li>Colon</li> <li>Prostate</li> <li>Breast</li> <li>Lung</li> </ol>
V. Other W. DK X. RF
Q017_1c. Is this your maternal or paternal grandfather?
1 MATERNAL (GO TO GRANDFATHER 2 (IF ANY) OR GRANDMOTHER) 2 PATERNAL (GO TO GRANDFATHER 2 (IF ANY) OR GRANDMOTHER)
W. DK (GO TO GRANDFATHER 2 (IF ANY) OR GRANDMOTHER) X. RF (GO TO GRANDFATHER 2 (IF ANY) OR GRANDMOTHER)
GRANDFATHER 2:
What type of cancer? At what age was he diagnosed?
(Q017_2aTyp) (Q017_2aAge) (Q017_2bTyp) (Q017_2bAge)
<ol> <li>Colon</li> <li>Prostate</li> <li>Breast</li> <li>Lung</li> </ol>
V. Other W. DK X. RF

Q017\_2c Is this your maternal or paternal grandfather?

**INDICATED IN Q017a** 

1 MATERNAL 2 PATERNAL
W. DK X. RF
*****
NOTE FOR Q018: ONLY DISPLAY THE CORRESPONDING NUMBER OF GRANDMOTHER SECTIONS INDICATED IN Q018a
Q018. Your grandmothers?
<ol> <li>YES → How many?(Q018a)</li> <li>NO (GO TO → Q019)</li> </ol>
W. DK (GO TO → Q019) X. RF (GO TO → Q019)
GRANDMOTHER 1:
What type of cancer? At what age was she diagnosed?
(Q018_1aTyp) (Q018_1aAge) (Q018_1b Typ) (Q018_1bAge)
<ul><li>1. Colon</li><li>3. Breast</li><li>4. Cervical</li></ul>
5. Lung 6. Ovarian 7. Endometrial
V. Other W. DK
X. RF
Q018_1c. Is this your maternal or paternal grandmother?
1 MATERNAL (GO TO GRANDMOTHER 2 (IF ANY) OR OTHER FAMILY Q019) 2 PATERNAL (GO TO GRANDMOTHER 2 (IF ANY) OR OTHER FAMILY Q019)
W. DK (GO TO GRANDMOTHER 2 (IF ANY) OR OTHER FAMILY Q019) X. RF (GO TO GRANDMOTHER 2 (IF ANY) OR OTHER FAMILY Q019)
GRANDMOTHER 2:
What type of cancer? At what age was she diagnosed?
(Q018_2aTvp) (Q018_2aAge)

(Q018_2bTyp) (Q018_	_2bAge)	
<ol> <li>Colon</li> <li>Breast</li> <li>Cervical</li> <li>Lung</li> <li>Ovarian</li> <li>Endometrial</li> </ol>		
V. Other W. DK X. RF		
Q018d. Is this your maternal or patern	al grandmother?	
1 MATERNAL 2 PATERNAL		
W. DK X. RF		
Q019. Is there anybody else in your far	mily who has been diagnosed with cance	1?
1. YES 0. NO (GO TO → Q021)	W. DK (GO TO → Q021) X RF (GO TO → Q021)	
Q020. WHO?		
(Q020a1)(Specify relationship)	(Q020b1) Type of cancer?	(Q020c1) Age at diagnosis?
(Q020a2)(Specify relationship)	(Q020b2) Type of cancer?	(Q020c2) Age at diagnosis?
(Q020a3)(Specify relationship)	(Q020b3) Type of cancer?	(Q020c3) Age at diagnosis?
<ol> <li>Niece</li> <li>Nephew</li> <li>Aunt</li> <li>Uncle</li> <li>Cousin</li> <li>Granddaughter</li> <li>Grandson</li> </ol>	<ol> <li>Colon</li> <li>Prostate</li> <li>Breast</li> <li>Cervical</li> <li>Lung</li> <li>Ovarian</li> <li>Endometrial</li> </ol>	W. DK X. RF
V. Other W. DK X. RF	V. Other W. DK X. RF	

#### \*\*\*\*\*

#### NOTE FOR Q021:

\*\*\*\*\*

<sup>\*</sup> IF RID = "2" CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER

<sup>\*</sup> INSERT PTFNAME IN BLANK

\*\*\*\* IF CASE HAS DIED, SKIP Q021 \*\*\*\* Q021. Now thinking back to your [father/brother/son] who had prostate cancer... Would you say his prostate cancer has... 1. Come back 2. Not come back 3. Spread to other parts of the body W. DK X. RF \*\*\*\* IF CASE HAS DIED, READ Q023 AS FOLLOWS:

"BEFORE HE DIED, HOW DID YOU SEE HIS TREATMENT FOR PROSTATE CANCER. WOULD YOU SAY IT WAS..." \*\*\*\*\*

Q023. Would you say his treatment and recovery from prostate cancer was...

- 1. Very hard
- 2. Somewhat hard
- 3. Not hard
- W. DK
- X. RF

Q024. Next, I'd like to ask about your feelings regarding prostate cancer.

How often do you think about your possibility of developing prostate cancer? Would you say ...

- 1. Very often
- 2. Once in a while
- 3. Never
- W. DK
- X. RF

Q025. How worried are you that you may get prostate cancer? Would you say ...

- 1. Very worried
- 2. Somewhat worried
- 3. Not worried
- W. DK
- X. RF

Q026. When you think about getting prostate cancer, how fearful are you? Would you say ...

- 1. Very fearful
- 2. Somewhat fearful
- 3. Not fearful
- W. DK
- X RF

Q027. Would you say you are v	ery nervous, somewhat nervous, or not nervous that you may get prostate cancer?
<ol> <li>VERY NERVOUS</li> <li>SOMEWHAT NERVOUS</li> <li>NOT NERVOUS</li> <li>DK</li> <li>RF</li> </ol>	
Q028. Do you think about getting	g prostate cancer more often than you would like to think about it?
1. YES 0. NO	W. DK X RF
**************************************	
Q030. Now, I'd like to ask yo	u a few questions about your health and some screening tests for prostate
During the past 12 months, hav	e you had a complete physical exam?
1. YES 0. NO	W. DK X RF
	find prostate cancer is the DRE or the "digital rectal exam". For this test a finger is for problems with the prostate and large bowel. Have you ever heard of a
1. YES 0. NO	W. DK X RF
Q032. Have you ever had a dig	ital rectal exam?
<ol> <li>YES</li> <li>NO (GO TO → Q034)</li> </ol>	W. DK (GO TO → Q034) X RF (GO TO → Q034)
Q033. When was your most re	cent digital rectal exam? Was it?
<ol> <li>Within the last 12 months</li> <li>1- 2 years ago</li> <li>2-3 years ago</li> <li>3-5 years ago</li> <li>More than 5 years ago</li> </ol>	S W. DK X RF
Q034. In addition to the digital This blood test is called a PSA	rectal exam, there is a special blood test used to check for prostate cancer. or "prostate specific antigen" test. Have your ever heard of a PSA?
1. YES 0. NO	W. DK X RF
Q035. Has your doctor (or nurs	se) ever recommended that you get a PSA blood test?
1. YES 0. NO	W. DK X RF

## Q036 DELETED

Q037. Have you ever had a PSA blood test?

1. YES

W. DK (GO TO → Q041)

0. NO (GO TO  $\rightarrow$  Q041)

X RF (GO TO → Q041)

Q038. How many PSAs have you had? Would you say ...?

1. One

W. DK

2. More than one

X RF

Q039. When was your most recent PSA? Was it ...?

1. Within the last 12 months

W. DK

2. 1- 2 years ago

X RF

5. 2-3 years ago

3. 3-5 years ago

4. More than 5 years ago

Q040. Why did you have this PSA? Was it for a health problem or was it part of a routine screening check-up, when you did not have any problems?

- 1. BECAUSE OF A HEALTH PROBLEM
- 2. PART OF A ROUTINE SCREENING CHECK UP

V. OTHER (Specify) \_\_\_\_\_(Q040s)

W. DK

X<sub>RF</sub>

Q041. Have you ever been to a urologist? A urologist is a doctor who treats diseases of the kidneys, bladder, testicles, and prostate.

1. YES

W. DK

0. NO

X RF

The next few questions have to do with tests that are used to detect other types of cancer.

Q042. A sigmoidoscopy or colonoscopy or "procto" is when a long *thin* bendable tube with a light on the end is inserted in the rectum and into the colon to check for problems. Have you ever heard of such an exam?

1. YES

W. DK

0. NO

X RF

Q043. Have you ever had a sigmoidoscopy or colonoscopy?

1. YES

W. DK (GO TO → Q045)

0. NO (GO TO → Q045)

X RF (GO TO → Q045)

Q044. When was your most recent sigmoidoscopy or colonoscopy? Was it ...?

1. Within the last 12 months

W. DK

2. 1-2 years ago

X RF

5. 2-3 years ago

- 3. 3-5 years ago
- 4. 5-10 years ago
- 6. More than 10 years ago

Q045. Another test that is done to check for colon cancer is the take home stool blood test, where the stool is tested for blood. For this test, you place a small amount of your stool on a card every day for 3 days and it is analyzed by a clinic. You are usually asked not to eat red meat or certain fruits and vegetables during this time. Have you ever heard of a stool blood test?

1. YES W. DK 0. NO X RF

Q046. Have you ever done a take home stool blood test?

1. YES

W. DK (GO TO -> Q048)

0. NO (GO TO  $\rightarrow$  Q048)

X RF (GO TO -> Q048)

Q047. When was your most recent test for blood in your stool? Was it ...?

1. Within the last 12 months

W. DK

2. 1-2 years ago

X RF

- 5. 2-3 years ago
- 3. 3-5 years ago
- 4. More than 5 years ago

Q048. Now, I'd like to ask you a few questions for statistical purposes only. Remember that your answers are confidential.

What is the highest level in school that you have completed?

NO SCHOOL GRADE SCHOOL	00 01	02	03	04	05	06	07	08
HIGH SCHOOL	09	10	11	12				
COLLEGE	13	14	15	16				
POST COLLEGE	17	18	19	20				
W DK X RF								

Q049. Were you born in the United States?

1. YES (GO TO Q →Q052)

W. DK

0. NO

X. RF

Q050. In what country were you born?

W. DK

X. RF

Q051.	How long have you lived in the U.S.?	Years:(Q051yy)	Months:(Q051mm)
	W. DK X. RF		
Q052.	What is your ethnicity?		
3. B. 8. 9. A. 5. 6.	Asian Indian Middle Eastern Eastern European Western European American Indian/Native American Pacific Islander (Hawaii, Guam, Samoa White/Caucasian GO T	O —> Q055) O —> Q056) O —> Q057) O> Q057) O> Q057) O> Q057) O> Q057) O> Q057) (GO TO> Q057) a, other South Pacific Island) (O	•
7.	, , , ,		O 10 -> Q053)
V.	Other: (specify)(Q052s2	2) (GO TO —> Q057)	
Q053.	W. DK X. RF Which race do you identify with most?		(GO TO -> Q057)
	W. DK X. RI	F	
Q054.	Are you? (GO TO —> Q057)  1. African American  2. West Indian   (includes Caribbean Islands)  3. Cuban	W. DK	(Q054s)
		X RF	
Q055.	Are you? (GO TO -> Q057)  1. Mexican  2. Mexican American  3. Chicana  4. Central American  5. South American	6. Puerto Rican 7. Cuban V. Other W. DK X RF	(Q055s)
Q056.	Are you? 1. Chinese 2. Japanese 3. Filipino 4. Vietnamese 5. Cambodian	<ul><li>6. Asian Indian</li><li>7. Indonesian</li><li>8. Korean</li><li>V. Other</li><li>W. DK</li><li>X RF</li></ul>	(Q56s)

Q057.	Which of the fo	llowing best	describes y	our total h	iousehold ii	ncome,	that is, th	e yearly ind	come of	all family
membe	ers living with yo	u? I don't ne	ed the exact	t amount	just a range	e. And i	remember	r, your answ	ver is co	nfidential.
Would	you say approx	cimately?								

1.	Less than \$10,000	( 0 - \$ 833/month)
2.	\$10,000 - 24,000	(\$ 833 - \$2,000/month)
3.	\$25,000 - 39,000	(\$2,083 - \$3,250/month)
4.	\$40,000 - 54,000	(\$3,333 - \$4,500/month)
5.	More than \$55,000	(More than \$4,583/month)
W.	DK	X RF

Q058. Are you currently married or living with someone as married?

- 1. YES
- 0. NO
- X. RF

Q058A. What is your date of birth, please? \_\_/\_/\_MM DD YY

Q059. Now I'm going to read a list of things that some people think make a man more likely to get prostate cancer. For each one, please tell me whether or not you believe it can make a man more likely to get prostate cancer.

\_\_\_\_\_ can make a man more likely to get prostate cancer?" "Do you believe Possibly RF Q059b. certain things you eat ...... W... X Q059e. drinking alcohol Q059g, exposure to harmful chemicals or radiation at work or in the community ...... 1... 0... 2... W.. X 

#### Q060. Who do you think gets prostate cancer most often?

- 1. Whites/Caucasians
- 2. Hispanics/Latinos
- 3. Black/African Americans
- 4. Asian/Asian Americans
- 5. Or do you think it makes no difference

W. DK X RF

Q061. How likely are you to get prostate cancer during your lifetime? Would you say ...?

- 1. Very likely
- 2. Somewhat likely
- 3. Not very likely

W. DK X RF

The next set of questions have to do with your beliefs about screening for prostate cancer.

		YES	NO	NO OPINION	DK	RF
Q065.	Is getting a PSA blood test important to you?	1	0	2	W	X
Q066.	Would it be difficult for you to pay for a PSA?	1	0	2	W	X.
Q071.	Would you have a problem getting transportation to the doctor?	1	0	2	W	X
Q064	Are you fearful of getting tested?	1	0	2	W	X
Q067.	Are you worried that screening will show you have prostate cancer?	1	0	2	W	X
	<b>Do you think</b> prostate cancer can be cured If found early?	1 1	0	2	W	X
Q070.	Do you think getting a DRE can cause sexual problems?	1	0	2	W	X
Q072.	Do you think you only need to get a PSA test if your doctor recommends it?	1	0	2	W	X
Q062	Were you aware that you should get a digital rectal exam every year?	1	. 0	2	w	X
Q063.	Did you know that you should have a PSA (prostate specific antigen) blood test every year?	1	0	2	W	X

Q069 DELETED

# Q073. Would you say you agree or disagree with the following statements. The benefits of getting a PSA blood test are greater than any inconvenience.

- Q074. You only need a prostate cancer screening test when you have symptoms.
- Q075. Going through prostate screening is too much trouble for what you get out of it.
- Q076. You do not have time to get tested.
  - 1. Agree
- W. DK
- 2. Disagree
- X RF
- Q077. How many of your friends and family do you think get checked for prostate cancer? Would you say ...?
  - 1. Most
  - 2. Few

W. DK

3. None

- X RF
- Q078. Do you think there is anything you can do to prevent getting prostate cancer?
  - 1. YES
  - 0. NO

- W. DK
- 2. MAYBE
- X RF
- Q079. Have you ever discussed your personal risk for getting prostate cancer with any friends or relatives?
  - 1. YES

W. DK

0. NO

- X RF
- Q080. Have you ever discussed your personal risk for getting prostate cancer with your doctor?
  - 1. YES

W. DK

0. NO

- X RF
- Q081. I'd like to ask you some questions about your insurance.

Do you have Medicare?

1. YES

W. DK

0. NO

- X RF
- Q082. Do you have Medicaid/Medical?
  - 1. YES

W. DK

0. NO

X RF

Q083. Do you have any other health insurance? 1. YES W. DK (GO TO -> Q085) 0. NO (GO TO -> (QO85) X RF (GO TO -> Q085) Q084 Is it ...? W Χ Q084a. An HMO with its own staff physicians and clinics YES NO DK RF (like Kaiser, FHP, or Maxicare) Q084b. A plan that lists physicians in private practice that you can YES NO DK RF use (like Prudential, Health Net, California Care, Care America) Q084c. Private insurance that will pay for any doctor you choose YES NO DK RF (like Blue Cross, Aetna, Travellers, or Mutual of Omaha) Q084s Other (Specify) YES NO DK RF NOTE: FOR Q085: IF Q081, Q082, OR Q083 = '1', ASK Q085, OTHERWISE GO TO Q086 Q085. Does your health insurance cover the cost of a PSA blood test? 1. YES W. DK 0. NO X RF Q086. A routine prostate cancer screening is for check-up purposes only, when no symptoms are present. For the next question please think about somebody like yourself who has a close relative with prostate cancer. At what age should he have his first PSA? Would you say at age ...? 1.30 2. 40 3. 50 W. DK 4.60 X RF Q087. How often should a man such as yourself have a PSA test? Would you say ...? 1. Every 6 months 2. Every year

- 3. Every 2-3 years

W. DK

4. Every 3-5 years

X RF

5. Every 5-10 years

\*\*\*\*\*

NOTE FOR Q088 & Q089:

\* IF RID = "2", CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER 33% OF SUBJECTS WILL RANDOMLY BE ASSIGNED TO RECEIVE SNR1; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR2; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR3. SNR3 WILL ONLY RECEIVE QUESTIONS: Q088 AND Q089. THEY WILL NOT RECEIVE A SCENARIO. \*\*\*\*\*

In this next section, I will read you a brief scenario followed by two questions. Please be patient and listen closely.

#### Q088. (SNR1) SCENARIO ONE: A scenario for a random 33% of the sample will read as follows:

Prostate cancer is the second leading cause of death from cancer in men. Having a **BROTHER**, **FATHER**, **SON** with prostate cancer increases your risk of getting it yourself. Doctors agree that early detection of prostate cancer is important. But doctors disagree about the widespread use of the PSA test to screen for prostate cancer.

Some doctors feel that the PSA blood test is not very accurate. For example, if a man has a **high PSA test**, this may mean that he has cancer, but it may also mean that his prostate is just swollen. To know for sure whether he has cancer or not, he would have to get a biopsy, which is a test where a small tissue sample is taken from the prostate for further checking.

Now, if a man has a **normal PSA blood level**, most of the time this means that he does not have cancer. But some men can have a normal PSA blood level and have cancer.

Currently, the PSA blood test is the only test available. Doctors feel that the PSA test can detect prostate cancer early, and 9 out of 10 cancers that are detected early can be cured. That's why many doctors, and the American Cancer Society, recommend that men over 40 have an annual PSA blood test, especially if they have a family member with prostate cancer.

Given what you have heard....

#### Q088 (SNR2) SCENARIO TWO: A scenario for a random 33% of the sample will read as follows:

Prostate cancer is the second leading cause of death from cancer in men. Having a BROTHER, FATHER, SON with prostate cancer increases your risk of getting it yourself. Doctors agree that early detection of prostate cancer is important. But doctors disagree about the widespread use of the PSA test to screen for prostate cancer.

Currently, the PSA blood test is the only test available. Doctors feel that the PSA test can detect prostate cancer early, and 9 out of 10 cancers that are detected early can be cured. That's why many doctors, and the American Cancer Society, recommend that men over 40 have an annual PSA blood test, especially if they have a family member with prostate cancer.

Some doctors feel that the PSA blood test is not very accurate. For example, if a man has a **high PSA test**, this may mean that he has cancer, but it may also mean that his prostate is just swollen. To know for sure whether he has cancer or not, he would have to get a biopsy, which is a test where a small tissue sample is taken from the prostate for further checking.

Now, if a man has a **normal PSA blood level**, most of the time this means that he does not have cancer. But some men can have a normal PSA blood level and have cancer.

Given what you have heard...

#### Q088 (SNR3) SCENARIO THREE: ASK QUESTIONS ONLY. THERE IS NO TEXT

How likely are you to ask your doctor (or nurse) about getting screened for prostate cancer?

W. DK

X RF

Very likely
 Somewhat likely

3. Not likely

Q089. How likely are you to get a PSA blood test within the next 12 months?

1. Very likely

W. DK

<ol> <li>Somewhat likely</li> <li>Not likely</li> </ol>	X RF

NOTE: Q090 AND 091 WERE DELETED DUE TO REDUNDANCY. SAME QUESTIONS AS Q088 AND Q089

#### **CLINICAL TRIALS**

1 YES

Q092. In this last section I will be asking you questions about clinical trials. A clinical trial is a research study done by doctors to find out how best to prevent a disease or treat a disease. Some trials are done with cancer patients to test different treatments. Other trials study if things like diet, exercise, or early detection can prevent diseases in healthy people.

Have you ever participated in a clinical trial?

• • •	NO (GO TO -> Q094)	X RF (GO TO -> Q094)	
Q093.	What kind of trial was it? Ple	ease specify:	
— W.	DK	X RF	

W DK (GO TO -> 0094)

Q094. Have you ever heard about the Prostate Cancer Prevention Trial or the Prostate, Lung, Colorectal, Ovarian Cancer Screening Trial?

1.	YES	W. DK
0.	NO	X RF

The following trials are very large studies involving thousands of healthy men. These trials are free of charge.

Q095. The Prostate Cancer Prevention Trial is a study to test whether the drug *finasteride* can prevent prostate cancer. In this trial, half of the men will be given the drug and half will be given a sugar pill. Men will not know if they are taking the drug or a sugar pill. At the end of 7 years, all men will have a biopsy of their prostate gland, in which a small sample of tissue is taken.

If you were asked to participate in a trial like this, would you participate?

Q096. Which of the following would be a reason for you not to participate in this trial?

	YES	NO	DK	RF
Q096a. having to take a pill daily for 7 years	1	0	W	X
Q096b, the possible side effects	1	0	W	X
Q096c. having to get a biopsy	1	0	W	Х

Q097. Another clinical trial is the PLCO. This is a study to see if a PSA blood test and a rectal exam can detect prostate cancer early. Half of the men will receive the PSA blood test and a rectal exam once a year for 4 years and half will not receive the tests at all. All the men, whether they receive the tests or not, will have to fill out a questionnaire each year.

If you were asked to participate in a trial like this, would you participate?

1. YES	W. DK
0. NO	X RF

Q098. Which of the following would be a reason for you not to participate in the trial?

	YES	NO	DK	RF
Q098a. having to get a blood test	1	0	W	X
Q098b. having to get a rectal exam	1	0	W	X
Q098c. having to fill out questionnaires	1	0	W	X

Q099. There is a new clinical trial that may be starting soon which will test whether Vitamin E and the mineral selenium can prevent prostate cancer. Men would have to take Vitamin E and selenium for a minimum of 7 years and a maximum of 12 years. This trial would not require men to take any other medications or get a biopsy.

If you were asked to participate in a trial like this, would you participate?

1. YES	W. DK
0. NO	X RF

Q100. Which of the following would be a reason for you not to participate in the trial?

	YES	NO	DK	RF
Q100a. having to take vitamins	1	0	W	X
Q100b. the length of the trial (7-12 yrs)	1	0	W	X

Q101. There are many reasons people give for not participating in clinical trials. Please tell me if any of the following reasons apply to you.

	Υ	'es	No	DK	RF
Q101a.	Afraid of being used as a guinea pig	1	0	W	X
Q101b.	Afraid you'll get cancer as a result of participating	1	0	W	X
Q101c.	Fear you will become impotent	1	0	W	X
Q101d.	Never thought about participating	. 1	0	W	X
Q101e.	Doctor never recommended participating	. 1	0	W	X
Q101f.	It is associated with homosexuality	1	0	W	Х

Q101g.	It is too uncomfortable or painful	0	W	X	
Q101h.	Can you think of any other reasons why you would not participate?	·			
		THE THEO.		•	

#### Q102. Please tell me whether you agree or disagree with the following statements.

	Agree	Disagree	No Opinion	DK	RF
Participating in clinical trials will help others.	1	0	2	W	X
Q103. Participating in clinical trials will prolong my life.	1	0	2	W	X
Q104. I may learn something that will benefit my health.	1	0	2	W	X

Q105. This concludes the survey. Before I hang up, I'd like to *briefly give you a few facts* about prostate cancer. Earlier in the interview, I asked you about what you think makes a man more likely to get prostate cancer. We think it's important to tell everyone we talk to what is scientifically known about prostate cancer. The following things are believed by scientists to make a man more likely to get prostate cancer. A combination of them increases the risk even more.

- older age (over 55 years old)
- having relatives with prostate cancer (especially a father, brother, or son)
- having a relative diagnosed before the age of 60
- being African American

You should also know that exercise and eating a low-fat diet may decrease your risk.

Q106. Many men believe other things make a man more likely to get prostate cancer which are not true. The following things are not related to prostate cancer.

- too much stress
- too much sex
- lack of sex
- sitting on cold surfaces

Also, drinking alcohol has not been scientifically proven to cause prostate cancer.

Q107. If you would like more information about prostate cancer, early detection and treatment, you can call the Cancer Information Service. Would you like the number?

- 1 YES [1-800-422-6237]
- 0 NO

NOTE FOR Q108M:

\*\*\*\*\*

PLEASE DISPLAY RADDRES1, RADDRES2, RCITY, RSTATE, RZIP, RPHONE1, RPHONE2, AND RPHONE3 FROM RELATIVE TRACKING DATABASE

111

Q108M

I would like to verify your address so that I can send you some information *on prostate cancer*. I would also like to get a telephone number, *of a relative or friend*, where we can reach you or leave you a message.

(REPEAT ADDRESS AND PHONE NUMBER ON FILE- SPECIFY NEW ADDRESS AND PHONE NUMBERS
\_\_\_\_\_\_(Q108M MEMO FIELD). (BLANK O.K.)

ENTER Y IF ADDRESS ETC. CHANGED, = = UPPER CASE ONLY

Q109. If we do a follow-up study in the future, may we contact you again?

1. YES

W. DK

0. NO

X. RF

On behalf of our project, I'd like to thank you for the time you dedicated to this survey. Good - bye.

!!!

RID:

THE INTERVIEW OF THIS RELATIVE IS OVER!

STATUS CODE OF THIS CASE'S INTERVIEW RECORD:

LANGUAGE OF INTERVIEW (E/S):

PREVIOUSLY RECORDED INTERVIEWER:

INTERVIEWER TO BE RECORDED:

2 OR 3 LETTER INITIALS, NO SPACE OR SYMBOL,
WILL BE CONVERTED TO UPPER CASE AUTOMATICALLY

	*****					
•	NOTE FOR 1st PARAGRAPH:  * IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' AND PSEX = '2' CHOOSE PAPA.					
		NAME A	ND PTL	NAME IN SECOND BLANK		
	Hola, mi nombre es, le estoy llamando del Centro de Cancer en UCLA Recibimos su nombre de su [HERMANO, PAPA, HIJO] [FIJAR NOMBRE]. ¿Le habló él sobre estudio?					
		□ SI □ NO		Me da gusto. Dejeme recordarle que Dejeme explicarle que		
	Estamos entrevistando a familiares cercanos de pacientes con cáncer de la próstata. La entrevista tomara aproximadamente 20 minutos y le preguntaremos sus opiniones, creencias sobre el cáncer, sus costumbres, y algunos antecedentes sobre su salud. Sus repuestas ayudaran a desarrollar programas para educar a las personas sobre la detección temprana del cáncer de la próstata.					
	¿Recientemente le enviamos algunos materiales explicandole el estudio, los recibió? Dejeme asegurarle que todas sus respuestas serán confidenciales. Toda información se utilizara solamente para este estudio. Ninguna información que lo identifique sera revelada sin su consentimiento. Usted puede parar la entrevista a cual quier momento.					
	Si usted desea y tiene alguna pregunta, le puedo dar el numero de la Doctora Bastani, quien conduce este estudio. (DR. BASTANI'S NUMBER IS: 310-206-9266; RESPONDENTS MAY CALL COLLECT).					
También le puedo dar el numero del Vice Canciller (310-825-8714) y de la Oficina de Protección a Sujetos de Investigación en UCLA, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095-1694, (310) 825-8714.						
	****					
		. ,		R IS "NO" SURVEY WILL BE TERMINATED. ENTER CODE "7" "3" TO SRVTERM1 IN RELATIVE TRACKING DATABASE		
	Q0A					
		(1)	SI ->	Continue		
		(0)	NO	Entiendo su decisión. Si tiene alguna pregunta sobre el cáncer de la próstata, la detección temprana, y sus tratamientos, puede llamar al Servicio de Información Sobre el Cáncer. ¿Le gustaría el numero? (1-800-422-6237 o 1-800-4-CÁNCER). Si cambia de opinión y quiere participar, por favor llamenos gratis al numero 1-877-278-8505. Gracias y adiós.		
	Q0B	¿Tiene	tiempo :	ahora?		

Dejeme asegurarle que ninguna respuesta es correcta o incorrecta. Estamos interesados en saber que es lo que usted siente y cree sobre el cáncer de la próstata.

¿Cuando le puedo llamar?\_ (GO TO LOGSHEET)

Continue

(1) SI -> (0) NO->

#### NOTE FOR Q001:

- \* ASK IF PLET1STA ='1' AND RAGE <>'--' OTHERWISE GO TO Q03
- \* IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' CHOOSE PAPA
- \* INSERT PTFNAME AND PTLNAME IN FIRST BLANK
- \* INSERT RAGE IN SECOND BLANK

\*\*\*\*\*

Q001 Dejeme empezar por verificar su edad. Usted tiene entre las edades de 40 a 75 anos, no?

1 SI

(GO TO ->Q04)

0 NO

W DK

X RF

NOTE: FOR Q003 IF PARTICIPANT IS UNDER 40 YEARS OF AGE OR OVER 75 YEARS OF AGE, THEY ARE NOT ABLE TO PATICIPATE. PLEASE SAY,...

(Q003w) Gracias. Agradezco su deseo de participar en este momento. Desafortunadamente, la encuesta telefónica es solamente para personas entre la edad de 40 a 75 años. ¿Tiene alguna pregunta para mi antes de terminar la llamada? Gracias por su tiempo. Adiós.

NOTE: AFTER READING Q003W, ENTER '0' VARIABLE "RELIG2" ALSO ENTER "7" IN SRVSTAT1
AND "7" IN SRVTERM1
\*\*\*\*\*\*

Q004 Ahora me gustaria hacerle algunas preguntas sobre su salud.

1 more me gostava mocero argunas propunas sopre su salua.

¿Alguna vez su doctor le dijo que tiene o que ha tenido algún tipo de cáncer?

1 SI

0 NO

(GO TO -> Q007)

W DK

(GO TO -> Q007)

X RF

(GO TO -> Q007)

\*\*\*\*

NOTE: IF Q005A OR Q005E OR Q005C = '2', SUBJECT IS INELIGIBLE FOR STUDY. GO TO Q006 AND END CALL. [MAKE NOTE IN RELATIVE TRACKING DATABASE VARIABLE RELIG2 = "2", SRVSTAT1 = "7", SRVTERM1 = "8"]

GO TO SUMMARY SCREEN BEFORE RETURNING TO LOG SHEET

Q005 ¿Que tipo de cáncer?

(Q05a) (Q05b) (Q05c)

- 1 COLON
- 2 PRÓSTATA
- 5 PULMONES

(GO TO -> Q007)

V Other -> specify\_W DK

(Q005v) (GO TO -> Q007)

W DK

(GO TO -> Q007)

X RF

(GO TO -> Q007)

Q006 Siento mucho oir esto. Le agradezco su deseo de participar en este estudio. Desafortunadamente, la encuesta telefónica se esta haciendo solamente con personas que no han tenido cáncer de la próstata. ¿Tiene algunas preguntas para mi antes de terminar la llamada? Gracias por su tiempo. Adiós.

Q007 En general, diria usted que su salud es...

- 1 excelente
- 2 muy buena
- 3 buena
- 4 regular
- 5 mala

WDK

XRF

Q008 ¿Alguna vez le ha dicho un doctor que tiene la próstata agrandada o hinchada? Esto también es conocido como hiperplasia prostático benigno (BPH).

1 SI

0 NO

W DK

XRF

* IF RI * INSE	RT PTFNAME IN FIRST BLAN D = "6", AFTER ASKING Q010		
Q010	Ahora me gustaría hacerle algunas preguntas sobre su familia y la salud de ellos. Comenzaremos con su [PAPÁ, HERMANO, HIJO] quien lo recomendó para este estudio. ¿Ademas de ser diagnosticado con cáncer de la próstata, ha sido el diagnosticado con algún otro tipo de cáncer?		
	1 SI 0 NO	(GO TO -> Q011)	
	W DK X RF	(GO TO -> Q011) (GO TO -> Q011)	
¿Que ti	po de cáncer?	¿A que edad fue diagnosticado?	
(Q010a (Q010a	n1) n2)	(Q010b1) (Q010b2)	
TIPO I	DE CÁNCER:		
	1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES		
	V OTRO W DK X RF		
Ahora	, le voy a leer una lista de sus otr	os familiares . Digame si algunos de ellos han tenido algun cancer.	
Q011	Su papa?		
	1 SI 0 NO	(GO TO -> Q012)	

(GO TO -> Q012) (GO TO -> Q012)

W DK X RF

(0011-	1)	(O011h1)			(2) su padrastro?
	1) 2)	(Q011b1) (Q011b2)			(Q011c)
TIPO D	E CÁNCER:				•
3 SEN	STATA				
V OTT W DK X RF					
Q012	¿Su MAMÁ?				
	1 SI 0 NO	,	(GO TO <b>-</b> >	Q013)	
	W DK X RF		(GO TO ->(		
Que tip	o de cáncer?	A que edad fue d	e edad fue diagnosticada?		Su MAMÁ es(1) su mamá biológica o (2) su madrastra
(Q012a (Q012a	1) 2)	(Q012b1) (Q012b2)	(W=DK (W=DK	X=RF) X=RF)	(Q012c)
TIPO D	E CÁNCER:				
6 OVA	O VIZ MONES				
V OTI W DK X RF					
	FOR Q013: DISPLAY THE CO	ORRESPONDING	NUMBER	OF BROTH	ER SECTIONS INDICATED IN Q013a
***** IF BRO	** THER WAS THE	"CASE" PHRASE	E Q013 AS:		

HAN SIDO ALGUNOS DE SUS DEMAS HERMANOS DIAGNOSTICADOS CON CANCER?

\*\*\*\*\*\*

1 SI -> Cuantos?	_ (Q013a)
0 NO	(GO TO -> Q014)
W DK	(GO TO -> Q014)
X RF	(GO TO -> Q014)
	,
HERMANO 1:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticado?
	•
(Q013_1aTyp)	(Q013_1aAge)
(Q013_1bTyp)	(Q013_1bAge)
TIPO DE CÁNCER:	
1 COLON	
2 PRÓSTATA	
3 SENO	
4 PULMONES	
V OTHER	
W DK	<u> </u>
X RF	
Q013_1c Su hermano es	
1 su hermano biológico	(GO TO -> BRO2, (IF ANY), SISTER Q014)
2 su medio hermano	(GO TO -> BRO2, (IF ANY), SISTER Q014)
3 su hermanastro	(GO 10 -> BRO2, (II AN1), SISTER Q014)
W DK	(GO TO -> BRO2, (IF ANY), SISTER Q014)
X RF	(GO TO -> BRO2, (IF ANY), SISTER Q014)
Q013_1d ¿Es su medio hermano por	parte de su MAMÁ o de su PAPÁ?
· -	
1 MAMÁ	
2 PAPÁ	
W DK	
X RF	
HERMANO 2:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticado?
(Q013_2aTyp) (Q013_2bTyp)	(Q013_2aAge) (Q013_2bAge)
(Q013_2019P)	(4017_201/20)
TIPO DE CÁNCER:	
1 COLON	

2 PRÓSTATA 3 SENO

```
W DK
X RF
Q013 2c Su hermano es ...
                           (GO TO -> BRO2, (IF ANY), SISTER Q014)
1 su hermano biológico
2 su medio hermano
3 su hermanastro
                           (GO TO -> BRO2, (IF ANY), SISTER Q014)
                           (GO TO -> BRO2, (IF ANY), SISTER Q014)
W DK
                           (GO TO -> BRO2, (IF ANY), SISTER Q014)
X RF
Q013 2d Es su medio hermano por parte de su MAMÁ o de su PAPÁ?
       1 MAMÁ
       2 PAPÁ
       W DK
       X RF
HERMANO 3:
                                    ¿A que edad fue diagnosticado?
¿Que tipo de cáncer?
                                    (Q13 3aAge)
                                                               (W=DK X=RF)
(Q013_3aTyp)_
                                                               (W=DK X=RF)
                                    (Q13_3bAge)__
(Q013_3bTyp)___
TIPO DE CÁNCER:
                                                                  V OTRO
1 COLON
                                                                  W DK
2 PRÓSTATA
                                                                  X RF
3 SENO
5 PULMONES
 Q013_3c Su hermano es...
 1 su hermano biológico
 2 su medio hermano
 3 su hermanastro
 W DK
 X RF
 Q013_3d ¿Es su medio hermano por parte de su MAMÁ o de su PAPÁ?
        1 MAMÁ
        2 PAPÁ
```

W DK X RF

V OTRO

\*\*\*\*\* Q014 ¿Algunas de sus hermanas?\_ (Q014a) 1 SI -> Cuantas? (GO TO -> Q015) 0 NO (GO TO -> Q015) W DK (GO TO -> Q015) X RF HERMANA 1: ¿A que edad fue diagnosticada? ¿Que tipo de cáncer? (Q014\_1aAge)\_ (Q014\_1aTyp)\_ (Q014\_1bAge)\_ (Q014\_1bTyp)\_\_\_\_ TIPO DE CÁNCER: 1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO V OTRO W DK X RF Q014 1c Su hermana es... (GO TO -> SISTER2, (IF ANY) OR SON Q015) 1 su hermana biológica 2 su media hermana (GO TO -> SISTER2, (IF ANY) OR SON Q015) 3 su hermanastra (GO TO -> SISTER2, (IF ANY) OR SON Q015) W DK X RF (GO TO -> SISTER2, (IF ANY) OR SON Q015) Q014\_1d ¿Es su media hermana por parte de su MAMÁ o de su PAPÁ? 1 MAMÁ 2 PAPÁ W DK X RF HERMANA 2: (Q014\_2bTyp)\_\_\_\_ ¿Que tipo de cáncer?

ONLY DISPLAY THE CORRESPONDING NUMBER OF SISTER SECTIONS INDICATED IN

(Q014\_2aTyp)\_\_

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NOTE FOR Q014:

A que edad fue diagnosticada?	·
(Q014_2aAge) (Q014_2bAge)	
TIPO DE CÁNCER:	·
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO	
V OTRO W DK X RF	
Q014_2c Su hermana es	
1 su hermana biológica	(GO TO -> SISTER3, (IF ANY), SON Q015)
<ul><li>2 su media hermana</li><li>3 su hermanastra</li></ul>	(GO TO -> SISTER3, (IF ANY), SON Q015)
W DK X RF	(GO TO -> SISTER3, (IF ANY), SON Q015) (GO TO -> SISTER3, (IF ANY), SON Q015)
Q014_2d ¿Es su media hermana por par	rte de su MAMÁ o PAPA?
1 MAMÁ 2 PAPA W DK X RF	
HERMANA 3:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticada?
(Q014_3aTyp) (Q014_3bTyp)	(Q014_3aAge) (Q014_3bAge)
TIPO DE CÁNCER:	
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO	

X RF Q014 3c Su hermana es.. 1 su hermana biológica (GO TO -> Q015) 2 su media hermana 3 su hermanastra (GO TO -> Q015) W DK (GO TO -> Q015) X RF (GO TO -> Q015) Q014\_3d ¿Es su media hermana por parte de su MAMÁ o de su PAPÁ? 1 MAMÁ 2 PAPA W DK X RF \*\*\*\* NOTE FOR Q015: ONLY DISPLAY THE CORRESPONDING NUMBER OF SON SECTIONS INDICATED IN Q015a IF A SON WAS THE CASE, PHRASE Q015 AS: HAN SIDO ALGUNOS DE SUS DEMAS HIJOS DIAGNOSTICADOS CON CANCER? Q015 ¿Han sido algunos de sus hijos diagnosticados con cáncer? 1 SI -> Cuantos? \_\_\_\_\_ (Q015a) 0 NO (GO TO ->Q016) W DK (GO TO ->Q016) X RF (GO TO ->Q016) HIJO 1: ¿Que tipo de cáncer? ¿A que edad fue diagnosticado? (Q015\_laAge)\_ (Q015\_laTyp)\_ (Q015\_1bTyp)\_\_\_\_ (Q015\_1bAge)\_\_\_ TIPO DE CÁNCER. 1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES **VOTRO** W DK XRF

V OTRO W DK

Q015_lc Es su hijo	
1 su hijo biológico 2 su hijo adoptivo 3 su hijastro	(GO TO $\rightarrow$ SON2, (IF ANY), OR DAUGHTER Q016) (GO TO $\rightarrow$ SON2, (IF ANY), OR DAUGHTER Q016) (GO TO $\rightarrow$ SON2, (IF ANY), OR DAUGHTER Q016)
W DK	(GO TO -> SON2, (IF ANY), OR DAUGHTER Q016)
X RF	(GO TO -> SON2, (IF ANY), OR DAUGHTER Q016)
HIJO 2: ¿Que tipo de cáncer?	¿A que edad fue diagnosticado?
(Q015_2aTyp) (Q015_2bTyp)	(Q015_3aAge) (Q015_3bAge)
TIPO DE CÁNCER:	
1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES	
V OTRO W DK X RF	
Q015_2c Es su hijo	
<ul><li>1 su hijo biológico</li><li>2 su hijo adoptivo</li><li>3 su hijastro</li></ul>	(GO TO -> SON3, (IF ANY), OR DAUGHTER Q016) (GO TO -> SON3, (IF ANY), OR DAUGHTER Q016) (GO TO -> SON3, (IF ANY), OR DAUGHTER Q016)
W DK X RF	(GO TO -> SON3, (IF ANY), OR DAUGHTER Q016) (GO TO -> SON3, (IF ANY), OR DAUGHTER Q016)
HIJO 3:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticado?
(Q015_3aTyp) (Q015_3bTyp)	(Q015_3aAge) (Q015_3bAge)
TIPO DE CÁNCER:	
1 COLON 2 PRÓSTATA 3 SENO 5 PULMONES	
V OTRO W DK X RF	
Q015_3c Es su hijo	
1 su hijo biológico 2 su hijo adoptivo 3 su hijastro	

W DK X RF

**	: *k xk	:xkx	***

*****	
NOTE FOR Q016: ONLY DISPLAY THE 0 *******	CORRESPONDING NUMBER OF DAUGHTER SECTIONS INDICATED IN Q016a
Q016 ¿Algunas de sus	hijas?
1 SI -> Cuantas?0 NO	(Q016a) (GO TO -> Q017)
W DK X RF	(GO TO -> Q017) (GO TO -> Q017)
HIJA 1: ¿Que tipo de cáncer?	¿A que edad fue diagnosticada?
(Q016_laTyp) (Q016_lbTyp)	(Q016_1aAge) (Q016_1bAge)
TIPO DE CÁNCER:	
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO	
V OTRO W DK X RF	
Q016_1c Es su hija	
<ol> <li>su hija biológica</li> <li>su hija adoptiva</li> <li>su hijastra</li> </ol>	(GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017) (GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017) (GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017)
W DK X RF	(GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017) (GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017)
HIJA 2: ¿Que tipo de cáncer?	¿A que edad fue diagnosticada?
(Q016_2aTyp) (Q016_2bTyp)	(Q016_2aAge) (Q016_2bAge)
TIPO DE CÁNCER:	
1 COLON	

3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS

' V OTI	20			
W DK				
X RF				
Q016_	2c Es su hija		•	
1 su hi	ja biológica	(GO TO ->DAUGHTER3, (IF A)	VY), OR GRANN	DFATHER Q017)
2 su hi	ja adoptiva	(GO TO ->DAUGHTER3, (IF A)	NY), OR GRANN	DFATHER Q017)
3 su hi	jastra	(GO TO ->DAUGHTER3, (IF A)	VY), OR GRANN	DFATHER Q017)
W DK		(GO TO ->DAUGHTER3, (IF A)		
X RF		(GO TO ->DAUGHTER3, (IF A)	NY), OR GRANN	DFATHER Q017)
НІЈА 3	:			
¿Que ti	ipo de cáncer?	¿A que edad fue diagnostic	ada?	
(Q016	_3aTyp)	(Q016_3aAge)	(W=DK	X=RF)
	_3bTyp)	(Q016_3bAge)	(W=DK	X=RF)
TIPO I	DE CÁNCER:	-		
1 COI	ON			
3 SEN				
4 CER	VIZ MONES			
6 OV				
7 END	OOMETRIO			
V OT	RO			
W DK X RF				
	3c Es su hija			
Q010_	•			
	1 su hija biológica			
	2 su hija adoptiva 3 su hijastra			
	W DV			
	W DK X RF			
*****				
		PONDING NUMBER OF GRANDF	ATHER SECTION	S INDICATED IN Q01
Q017	¿Algunos de sus abuelos	?		
	1 SI> Cuantos?			
	0 NO	(GO	TO -> Q018)	
	W DK	(GO	TO -> Q018)	
	X RF		TO -> Q018)	

¿Que tip	oo de cáncer?	¿A que edad fue diagnosticado?
	1aTyp) 1bTyp)	(Q017_2aAge) (Q017_2bAge)
TIPO D	E CÁNCER:	
1 COLO 2 PRÓS 3 SENO 5 PULM	STATA O	
V OTR W DK X RF	0	
Q017_1	c ¿Es su abuelo mate	erno o paterno?
	1 MATERNO 2 PATERNO	(GO TO GRANDFATHER2 (IF ANY) OR GRANDMOTHER Q018) (GO TO GRANDFATHER2 (IF ANY) OR GRANDMOTHER Q018)
	W DK X RF	(GO TO GRANDFATHER2 (IF ANY) OR GRANDMOTHER Q018) (GO TO GRANDFATHER2 (IF ANY) OR GRANDMOTHER Q018)
ABUEL	O 2:	
(Q017_	oo de cáncer? 2aTyp) 2bTyp)	¿A que edad fue diagnosticado?  (Q017_2aAge) (Q017_2bAge)
TIPO D	E CÁNCER:	
1 COLO 2 PRÓS 3 SENO 5 PULI	STATA	
V OTI W DK X RF	RO	
Q017_2	c ¿Es su abuelo mate	rno o paterno?
	1 MATERNO 2 PATERNO	
	W DK X RF	
	FOR Q018:	RESPONDING NUMBER OF SISTER SECTIONS INDICATED IN Q018a

14

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1 SI -> Cuantas?	(Q018a)
0 NO	(GO TO -> Q019)
W DK X RF	(GO TO -> Q019) (GO TO -> Q019)
ABUELA 1:	
¿Que tipo de cáncer?	¿A que edad fue diagnosticada?
(Q018_1aTyp) (Q018_1bTyp)	(Q018_2aAge) (Q018_2aAge)
TIPO DE CÁNCER:	
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO	· •
V OTRO W DK X RF	
Q018_1 ¿Es su abuela mate	rna o paterna?
1 MATERNA 2 PATERNA	(GO TO GRANDMOTHER2 (IF ANY) OR OTHER FAMILY Q019) (GO TO GRANDMOTHER2 (IF ANY) OR OTHER FAMILY Q019)
W DK X RF	(GO TO GRANDMOTHER2 (IF ANY) OR OTHER FAMILY Q019) (GO TO GRANDMOTHER2 (IF ANY) OR OTHER FAMILY Q019)
ABUELA 2: ¿Que tipo de cáncer?	¿A que edad fue diagnosticada?
(Q018_2aTyp) (Q018_2bTyp)	(Q018_2aAge) (Q018_2bAge)
TIPO DE CÁNCER:	
1 COLON 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIO	
V OTRO W DK X RF	

Q018\_2c ¿Es su abuela materna o paterna? 1 MATERNA 2 PATERNA W DK X RF ¿Hay alguien más en su familia que haya tenido cáncer? Q019 1 S.I 0 NO (GO TO -> Q021) W DK (GO TO -> Q021) X RF (GO TO -> Q021) Q020 ¿Quien? ¿Relación? ¿Tipo de cáncer? ¿A que edad fue diagnosticado/a? (Q021a1)\_ (Q021b1)\_ (Q021c1)\_ (Q021a2) (Q021b2)\_ (Q021c2)\_ (Q021a3)\_ (Q021b3)\_ (Q021c3)\_ RELACIÓN 1 SOBRINA 2 SOBRINO 3 TÍA 4 TÍO 5 PRIMO/A 6 NIETA 7 NIETO V OTRO W DK X RF TIPO DE CÁNCER: 1 COLON 2 PRÓSTATA 3 SENO 4 CERVIZ 5 PULMONES 6 OVARIOS 7 ENDOMETRIAL

V OTRO W DK X RF

•	* IF RII						
	IF CAS	SE HAS DIED, SKIP Q021					
	****	**					
	Q021	Con respeto a su [PAPA, HERMANO, HIJO] quien tuvo cáncer de la próstata diria usted el cancer se le ha					
		<ul><li>1 regresado</li><li>2 no ha regresado</li><li>3 desarrollado a otras partes del cuerpo</li></ul>					
		W DK X RF					
		FOR Q023 IF CASE HAS DIED READ: ANTES DE EL MORIR, COMO VIO USTED SU MIENTO DE CANCER. DIRIA QUE FUE					
	Q023	Diria usted que su tratamiento y su recuperación del cáncer de la próstata fue					
		1 muy dificil 2 un poco dificil 3 nada dificil					
		W DK X RF					
	Q024	Ahora me gustaría hacerle unas preguntas acerca de sus sentimientos sobre el cáncer de la próstata.					
		¿Con que frecuencia piensa usted en la posibilidad de desarrollar cáncer de la próstata? Diría que					
		1 muy seguido 2 de vez en cuando 3 nunca					
		W DK X RF					
	Q025	¿Que tan preocupado esta de que pueda desarrollar cáncer de la próstata? Diría que					
	<ul><li>1 muy preocupado</li><li>2 algo preocupado</li><li>3 nada preocupado</li></ul>						
		W DK X RF					
	Q026	¿Cuando piensa en la posibilidad de desarrollar cáncer de la próstata, que tan temeroso se pone? Diría que					
		1 muy temeroso W DK 2 algo temeroso X RF 3 nada temeroso					

Q027	¿Diría que usted esta muy nervioso, al cáncer de la próstata?	go nervioso, o nada nervioso de que pueda desarrollar
	1 MUY NERVIOSO 2 ALGO NERVIOSO 3 NADA NERVIOSO	
	W DK X RF	
Q028	¿Piensa, mas de lo que usted desea, en	que pueda desarrollar cáncer de la próstata?
	1 SI 0 NO	
	W DK X RF	
Q030	Ahora le quiero hacer unas pregunts cancer de la prostata.	as sobre su salud y algunos de los examenes para el
	Durante los últimos 12 meses, ha tenio	do un examen físico completo?
	1 SI 0 NO	
	W DK X RF	
Q031	del recto. Para este examen un dedo es	el cáncer de la próstata es el DRE o sea examen digital sintroducido en el recto para examinar el área por algún mayor. ¿Alguna vez usted ha oído hablar de este
	1 SI 0 NO	
	W DK X RF	
Q032	¿Ha tenido alguna vez un examen digi	tal del recto- DRE?
	1 SI 0 NO (GO TO - C	2034)
	W DK (GO TO - C	
Q033	¿Cuando fue su examen mas reciente o	digital del recto?
	1 en los últimos 12 meses 2 de 1 a 2 años 5 de 2 a 3 años 3 de 3 a 5 años 4 mas de 5 años	
	W DK X RF	

Q034	En adición al examen digital del recto, existe un análisis de sangre que se usa para detectar cáncer de la próstata. Este análisis de sangre se llama PSA o sea "antígenos específicos de l próstata". ¿Ha tenido usted alguna vez un análisis de sangre PSA?					
	1 SI 0 NO					
	W DK X RF					
Q035	¿Le ha recomendado su doctor (o enfermera) que se haga u	un análisis de sangre PSA?				
	1 SI 0 NO					
	W DK X RF					
Q037	¿Ha tenido usted alguna vez un análisis de sangre PSA?					
	1 SI 0 NO (GO TO Q041)					
	W DK (GO TO Q041) X RF (GO TO Q041)					
Q038	¿Cuantos análisis PSA ha tenido? ¿Diría que?					
	1 uno 2 mas de uno					
	W DK X RF					
Q039	¿Cuando fue su análisis de sangre PSA mas reciente? Dirís	a que fue				
	1 en los últimos 12 meses 2 de 1 o 2 años 5 De 2 a 3 años 3 de 3 a 5 años 4 mas de 5 años	W DK X RF				
Q040	¿Por que le hicieron el análisis PSA? Fue por algún proble examen de rutina?	ema de salud o como parte de un				
	1 POR UN PROBLEMA DE SALUD 2 PARTE DE UN EXAMEN RUTINARIO					
	V OTHER (Specify) W DK X RF	(Q040s)				

Ų041	¿Alguna vez a ido con un urologo? Un urologo es un doctor que se especializa en la problemas de los rifiones, vesícula, testículo y próstata.
	1 SI 0 NO
	W DK X RF
Las sign	uientes preguntas son acerca de examenes utilizados para detectar otros tipos de cancer.
Q042	Una sigmoidoscopia o colonoscopia es cuando un instrumento largo y flexible con una luz terminal se introduce al recto y al colon para examinar posibles problemas. ¿Había usted oído hablar de este examen?
	1 SI 0 NO
	W DK X RF
Q043	¿Ha tenido usted alguna vez una sigmoidoscopia o una colonoscopia?
	1 SI 0 NO (GO TO Q045)
	W DK (GO TO Q045) X RF (GO TO Q045)
Q044	¿Cuando fue su mas reciente sigmoidoscopia o colonocopia? Diria usted que fue
	1 en los últimos 12 meses 2 de 1 o 2 anos
	5 de 2 a 3 anos 3 de 3 a 5 años
	4 de 5 a 10 años 6 mas de 10 anos
	W DK X RF
Q045	Otro análisis que se hace para detectar el cáncer del colon es el examen de excremento que detecta si hay sangre en el excremento. Para este examen usted pone una poco de su excremento en una tarjeta, todos los dias por 3 días y es analisado por una clinica. Usualmente se le pedirá que se abstenga de comer carne roja o ciertas frutas y vegetales durante este tiempo. ¿Alguna vez ha oído hablar del examen de excremento que detecta sangre?
	1 SI 0 NO
	W DK X RF
Q046	¿Alguna vez se ha hecho en casa el examen de excremento que detecta sangre?
	1 SI 0 NO (GO TO Q048)

Q047	¿Cuando se hizo el examen mas reciente	de exc	emer	ito pa	ara de	etecta	r san	gre?	Diria	que fue
	1 en los últimos 12 meses 2 de 1 o 2 anos									
	5 de 2 a 3 anos									
	3 de 3 a 5 años									
	4 mas de 5 afíos									
	W DK X RF									
	V 10.									
Q048	Ahora le voy hacer algunas preguntas so Recuerde que sus preguntas son confider		para	proj	oósito	s de	estadi	ística	s gene	rales.
	¿Cual es el nivel de educación mas alto o	que uste	d ha	comp	oletad	lo?				
	NINGUNA ESCUELA	00								
	ESCUELA ELEMENTARÍA		02	03	04	05	06	07	08	
	SECUNDARIA	09	10	11	12					
	UNIVERSIDAD	13	14	15	16					
	MAS DE UNIVERSIDAD (4 YRS)	17	18	19	20					
	W DK									
	XRF									
Q049	¿Nació usted en los Estados Unidos?									
	1 SI	(GO	TO -	> Q0	52)					
	0 NO	·		_	·					
	W DK X RF									
Q050	¿En que pais nació?									
	WDK									
	XRF									
Q051	¿Cuanto tiempo tiene viviendo en los Es									
	(Q051yy)Años: (Q05	1mm)N	ieses:	٠,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,						
	W DK									
	X RF									
Q052	¿Se considera Usted?									
	1 Afro-Americano				1	(GO '	TO ->	Q05	54)	
	2 Hispano / Latino						TO ->			
	3 Asiático / Asiático-Americano						TO ->			
	B Indio Asiatico					•	TO ->	-	•	
	8 Europeo					•	TO ->	-	-	
	9 Furança del este					•	TO	-	•	

	A Europeo del oeste 5 Americano Indigena/ Americano Nativo 6 Isleno del Pacifico (Hawaii, Guam Samoa, oth	(GO TO -> Q055) (GO TO -> Q057) er South Pacific Island) (GO TO -> Q057)
	<ul><li>4. Blanco (GO TO -&gt; Q057)</li><li>7 de dos razas o de diversas razas (specify)</li></ul>	(Q052s1) (GO TO -> Q053)
	V. Other: (specify) (Q052s2) (	(GO TO> Q057)
	W DK X RF	
Q053	¿Con cual nacionalidad se identifica mas?	
Q054	Es usted	
	<ol> <li>Afro-Americano</li> <li>Indio del Oeste (incluye Islas del Caribe)</li> <li>Cubano</li> <li>Sur Americano</li> <li>Puertorriqueño</li> </ol>	
	V OTHER (Q054 W DK X RF	s)
Q055	Es Usted	
	1 Mexicano 2 Mexicano Americano 3 Chicano 4 Centro Americano 5 Sur Americano 6 Puertorriqueño 7 Cubano	
	V Other (Specify) W DF X RF	(Q055s)
Q056	Es Usted	
	<ul> <li>1 Chino</li> <li>2 Japones</li> <li>3 Filipino</li> <li>4 Vietnamita</li> <li>5 Camboyano</li> <li>6 Indígena Asiático</li> <li>7 Indonesio</li> <li>8 Coreano</li> </ul>	
	V OTHER(Q056s) W DK X RF	

QUS/	Cual de las siguientes cantidades mejor describe el ingreso total en su hogar, o sea el in total de todas las personas viviendo con usted. No necesito una cantidad exacta, solamo estimado. Recuerde, sus respuestas son confidenciales. Diría que aproximadamente							
	1 Menos de \$10,000 (0-833.33/mes) 2 \$10,000 - 24,000(833.33 - 2000/mes) 3 \$25,000 - 39,000 (2083.33 - 3250/mes) 4 \$40,000 - 54,000(3333.33 - 4583.33/mes) 5 mas de \$55,000 (mas de 4,583.33/mes)							
	W DK X RF							
Q058	¿Es usted casado o esta viviendo como casado?							
	1 SI 0 NO							
	W DK X RF							
Q058A	¿Cual es su fecha de nacimiento, por favor?\\ ?  MM DD YY							
Q059	Ahora le voy a leer una lista de cosas que algunas personas piensan que hacen a un hombre mas probable de desarrollar cáncer de la próstata. Para cada una de estas preguntas digame susted cree o no cree que hace a un hombre mas probable de desarrollar cáncer de la próstata.							
	"¿Cree usted que hace a un hombre mas probable de desarrollar cáncer de la próstata"?							
Q059b Q059c Q059d Q059e Q059f Q059g Q059h Q059i	edad avanzada? ciertos alimentos? demasiado "estrés" ? tener familiares con cáncer de la próstata? beber alcohol? falta de ejercicio o actividad física del cuerpo? estar expuesto a químicos o radiación en el empleo o en la comunidad? tener demasiadas relaciones sexuales? sentarse sobre una superficie fría? ausencia de relaciones sexuales?							
	1 SI 0 NO 2 POSIBLEMENTE							
	W DK X RF							
Q060	¿Quien cree usted que desarrolla cáncer de la próstata con mas frecuencia? Diría que							
	1 Blancos 2 Hispanos/Latinos 3 Afro-Americanos 4 Asiáticos/Asia-Americanos 5 No hay diferencia							
	W DK X RF							

	2 poco probable 3 nada probable
	W DK X RF
_	uientes preguntas son relacionadas con sus creencias acerca del análisis de sangre PSA- Antígenos cos de la próstata.
Q065	¿Es importante para usted tener un análisis de sangre PSA?
Q066 Q071	¿Le seria a usted difícil pagar los costos de un análisis de sangre PSA? ¿Usted piensa que tendrá problemas en obtener transportación para ir a su cita con el doctor?
Q071 Q064	¿Esta temeroso de que le hagan estos análisis?
Q067	¿Tiene temor que durante estos análisis demuestren que usted tiene cáncer de la próstata?
Q068	¿Cree Ud que se puede curar el cáncer de la próstata si es encontrado temprano?
Q070	¿Usted piensa que los análisis de la próstata pueden causar problemas sexuales?
Q072	¿Cree usted que solamente necesita examinarse la sangre con un análisis de PSA nomas cuando un
Q062	doctor lo recomienda?
Q063	¿Sabia usted que debe de hacerse un análisis de sangre PSA cada año?
	1 SI
	0 NO
	2 NINGUNA OPINION
	W DK X RF
Q073	Diría usted que esta de acuerdo o no esta de acuerdo con las siguientes declaraciones:
	Los beneficios de un examen de sangre PSA son mayores que cualquier inconveniencia.
	1 esta de acuerdo 2 no esta de acuerdo
	W DK
	X RF
Q074	Uno solamente necesita un análisis preventivo de la próstata cuando tiene los síntomas.
	1 esta de acuerdo 2 no esta de acuerdo
	W DK X RF
Q075	Es mucha molestia tener que examinarse para el cáncer de la próstata y poco el beneficio que se obtiene.
	1 esta de acuerdo 2 no esta de acuerdo

¿Que tan probable es que usted desarrolle cáncer de la próstata durante su vida? Diría usted...

. Q061

1 muy probable

Q076	Usted no tiene tiempo para hacerse estos análisis,
	1 esta de acuerdo
	2 no esta de acuerdo
	WDK
	X RF
Q077	¿Cuantos de sus amigos o familiares se hacen los análisis de cáncer de la próstata? Diria usted que
	1 la mayoría
	2 algunos
	3 ninguno
	WDK
	X RF
Q078	¿Piensa usted que puede hacer algo para prevenir el cáncer de la próstata?
	1 \$I
	0 NO
	2 tal vez
	W DK
	XRF
0070	
Q079	¿Alguna vez ha discutido su riesgo personal de desarrollar cáncer de la próstata con algún amigo o familiar?
	Special Specia
	1 SI
	0 NO
	W DK
	XRF
Q080	¿Alguna vez ha discutido su riesgo personal de desarrollar cáncer de la próstata con su doctor?
	1 SI
	0 NO
	W DK
	XRF
Q081	Ahora me gustaria hacerle preguntas sobre su seguro medico.
	¿Esta usted cubierto por Medicare?
	Change and addition has vitamental
	1 SI
	0 NO
	W DK
	X RF

QU82	\$11ene usted Medicard/Medicar?		
	1 SI		
	0 NO		
	W DK X RF		
Q083	¿Tiene algún otro seguro medico?		
	1 SI		
	0 NO	(GO TO ->Q084)	
	W DK X RF	(GO TO ->Q084) (GO TO ->Q084)	
Q084	¿Es?		
	Un HMO con sus propios médicos y Es un plan con una lista de médico Care, or Care America)?		
Q084c	Seguro medico privado que paga po	or cualquier doctor que usted es	scoja (como Blue Cross, Aetna,
Q084s	Travellers, or Mutual of Omaha)  Es otro tipo de seguro medico? Spe	cify	
•	1 SI 0 NO		
	W DK X RF		
***** IF Q08,	1, Q082 OR Q083 = "1", ASK Q085	, OTHERWISE SKIP TO Q08	5.
Q085	¿Cubre su seguro medico el costo d	e un análisis de sangre PSA?	
	1 YES 0 NO		
	W DK X RF		
Q086		na pregunta, piense en alguie	o solamente, cuando no hay ningúi n como usted que tiene un familiar
	¿A que edad debe alguien como us	ted empezar a hacerse este exa	men? Diría que a la edad de
	1 30 2 40 3 50 4 60	W X	DK RF

Q087 ¿Con que frecuencia debe un hombre como usted hacerse un análisis de sangre PSA Antígenos específicos de la próstata) diria usted ....?

- 1 Cada 6 meses
- 2 Cada ano
- 3 Cada 2-3 anos
- 4 Cada 3-5 anos
- 5 Cada 5-10 anos

WDK

X RF

#### \*\*\*\*\*

NOTE FOR Q088 & Q089:

\*IF RID = "2" CHOOSE HIJO; IF RID = "4" CHOOSE HERMANO; IF RID = "6" CHOOSE PADRE, 33% OF SUBJECTS WILL BE RANDOMLY BE ASSIGNED TO RECEIVE SNR1; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR2; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR3. SNR3 WILL ONLY RECEIVE QUESTIONS Q088 AND Q089. THEY WILL NOT RECEIVE A SENARIO.

#### \*\*\*\*\*

En esta proxima seccion, le voy a leer un breve scenario y dos preguntas. Por favor tenga paciencia,

Q088. (SNR1) Escenario uno: Un escenario al azar para un 33% de la muestra de los participantes; esto se leerá de la siguiente manera:

El cáncer de la próstata es la segunda causa de muerte de cancer en los hombres. Si usted tiene un hermano, padre, hijo con cáncer de la próstata esto aumenta su riesgo para desarrollar cáncer de la próstata. Los doctores están de acuerdo que la detección temprana de cáncer de la próstata es muy importante. Pero los doctores están en desacuerdo con el uso extendido de PSA como un análisis preventivo.

Algunos doctores sienten que el análisis PSA no es muy preciso. Supongamos que un hombre tiene niveles altos de PSA en su sangre. Esto puede significar que el tiene cáncer, pero también puede significar que su próstata esta inflamada. Porque uno no sabe lo que realmente es, el paciente puede necesitar una biopsia para saber con seguridad. Durante una biopsia una muestra pequeña de tejido de la próstata es extraída y analizada.

Ahora, supongamos que un hombre tiene un nivel normal de PSA en su sangre. La mayor parte del tiempo un nivel normal de PSA significa que la persona no tiene cancer. Sin embargo, un hombre puede tener un nivel normal de PSA en su sangre y si tener cancer.

Actualmente, el análisis de sangre PSA es el único análisis disponible Los doctores piensan que un análisisde sangre PSA puede detectar el cáncer tempranamente. De cada 10 canceres que son detectados temprano 9 pueden ser curados. Entonces, los doctores, como también la Asociación Americana de Cáncer, recomiendan altamente que hombres mayores de 40 años tengan un examen anual de sangre PSA, especialmente si tiene un miembro de la familia que haya tenido cáncer de la próstata.

Dado a lo que ha escuchado.....

Q088. (SNR2) Escenario dos: Un escenario al azar para un 33% de la muestra de los participantes; esto se leerá de la siguiente manera;

El cáncer de la próstata es la segunda causa de muerte del cancer en los hombres. Si usted tiene un [hermano, padre, hijo] con cáncer de la próstata esto aumenta su riesgo para desarrollar cáncer de la próstata. Los doctores están de acuerdo que la detección temprana de cáncer de la próstata es muy importante. Pero los doctores están en desacuerdo con el uso extendido de PSA como un análisis preventivo.

Actualmente, el análisis de sangre PSA es el único análisis disponible. Los doctores piensan que un análisis de sangre PSA puede detectar el cáncer tempranamente. De cada 10 canceres que son

detectados temprano 9 pueden ser curados. Es por eso que muchos doctores, como también la Asociación Americana de Cáncer, recomiendan altamente que hombres mayores de 40 años tengan un examen anual de sangre PSA, especialmente si tiene un miembro de la familia que haya tenido cáncer de la próstata.

Algunos doctores sienten que el análisis PSA no es muy preciso. Supongamos que un hombre tiene niveles altos de PSA en su sangre. Esto puede significar que el tiene cáncer, pero también puede significar que su próstata esta inflamada. Porque uno no sabe lo que realmente es, el paciente puede necesitar una biopsia para saber con seguridad. Durante una biopsia una muestra pequeña de tejido de la próstata es extraída y analizada.

Ahora, supongamos que un hombre tiene un nivel normal de PSA en su sangre. La mayor parte del tiempo un nivel normal de PSA significa que la persona no tiene cáncer. Sin embargo, un hombre puede tener un nivel normal de PSA en su sangre y si tener cáncer.

Dado lo que ha escuchado.....

# Q088. (SNR3) SCENARIO THREE: NO TEXT ONLY QUESTIONS ASKED 33% OF PARTICIPANTS.

Que tan probable es que usted le pida a su doctor/a (o enfermera/o) que le hagan un análisis para el cáncer de la próstata?

- 1 Muy probable
- 2 Algo probable
- 3 Nada probable

W DK

XRF

Q089 ¿Que tan probable es que usted se haga un análisis de sangre PSA en los próximos 12 meses?

1 muy probable

2 algo probable

W DK

3 nada probable

X RF

### PRUEBAS CLÍNICAS

Q092 En esta ultima seccion le hare preguntas sobre las pruebas clinicas. Una prueba clinica es un estudio de experimentación hecho por doctores para encontrar la mejor manera de prevenir una enfermedad o tratar una enfermedad. Algunas pruebas son hechas con pacientes de cáncer para probar diferentes tratamientos. Otros estudios examinan cosas como si la dieta, ejercicio, o detección temprana puede prevenir una enfermedad en personas saludables.

¿Alguna vez a participado en una prueba clínica?

1 SI

0 NO

W DK (GO TO Q092)

X RF (GO TO Q092)

W DK

Q094	¿Alguna vez ha oído hablar de las pruebas preventivas para el cáncer de la próstata, pulmones, colon, o cáncer de los ovarios?						
	1 SI 0 NO						
	W DK X RF						
Q095	Las siguientes pruebas son estudios gra Estas pruebas son gratis.	ndes las cuale	es inclu	yen mile	s de hombr	es saludables.	
mitad d	La prueba de Prevención de Cáncer de mento finasteride puede prevenir cáncer le las hombres y a la otra mitad se les da nbres tendrán una biopsia de la glándula.	de la próstata ará una pastil	a. En la de az	este estu zúcar. A	dio se le da l terminar l	rá la droga a los 7 anos, todo	
	¿Si le pidieran que participe en un estudie	o como este, pa	articipa	ría?			
	1 SI 2 NO			W DK X RF			
Q096	¿Cual de las siguientes seria una razón po	or la cual no pa	articipa	ría en est	e estudio?		
			SI	NO	DK	RF	
Q096a	tener que tomar una pastilla diariamente siete años	por	1	0	W	X	
Q096b	los posibles efectos secundarios		1	0	W	X	
Q096c	tener una biopsia		1	0	W	X	
Q097	Otra prueba clínica es el PLCO. Es un análisis del recto puede detectar cáncer recibirán el análisis de sangre PSA y un mitad no recibirá ningún análisis. Todo recibido los análisis tendrán que llenar	r de la próstat n examen del os los hombres	ta temp recto u s, que h	rano. L na vez a iayan re	a mitad de l año por 4	los hombres anos, y la otra	
	¿Si le pidieran que participe en un estudi	o como este, p	articipa	ría?			
	1 SI 2 NO						
	W DK X RF						
Q098	Cual de las siguientes seria una razón po	r la cual no pa SI	-	ía en este NO	e estudio? DK	RF	
Q098a	tener que recibir un análisis de sangre	1	0	.,0	W	X	
•	ener que recibir un análisis del recto	I	0		W	X	29

Q094

Q099	Hay una nueva prueba clínica que comenzara pronto. Hombres tendran que tomar la vitamina E y el mineral selenio y mirara si la vitamina E y el selenio puede prevenir cancer de la prostata por un mínimo tiempo de 7 años y un máximo tiempo de 12 años. Este estudio no requiere tomar medicamentos o tener uno biopsia.							
	¿Si le pidieran que participe en un estudio c	como este, pa	rticiparía?					
	1 SI 2 NO							
	W DK X RF							
Q100	¿Cual de las siguientes seria una razón por	la cual no pa	rticiparía en es	te estudio?				
		SI _	NO	DK	RF			
Q100a	el tener que tomar vitaminas	1	0	w	X			
Q100b	la duración del estudio (7-12años)	1	0	W	X			
Q101b	Hay muchas razones por las cuales algun digame si algunas de las siguientes razone.  Tener miedo de ser utilizado como un anim Tener miedo de desarrollar cáncer como un Temor de quedar impotente	es le aplican alito de prue	a usted:		dínicas. Por f	favor		
Q101d	Nunca ha pensado poder participar							
	Doctor nunca le recomendó participar Es asociado con la homosexualidad							
Q101g	Es muy incómodo o doloroso	-						
Q101h	Puede pensar en otras razones por la cual n	o participa?_ 			· -			
	1 SI 0 NO							
	W DK				•			
	X RF							
Q102	Por favor digame si usted esta de a frases:	icuerdo o i	10 esta de a	cuerdo con	las siguien	ites		
	El participar en pruebas medicas pue	de ayudar a	otros.					
	<ol> <li>De acuerdo</li> <li>No esta de acuerdo</li> <li>No tengo ninguna opinión</li> </ol>							

W DK

- Q103 El participar en pruebas medicas me va a prolongar la vida.
  - 1 De acuerdo
  - 0 No esta de acuerdo
  - 2 No tengo ninguna opinión

W DK

X RF

- Q104 Yo puedo aprender algo que beneficie mi salud.
  - 1 De acuerdo
  - 0 No esta de acuerdo
  - 2 No tengo ninguna opinión

W DK

X RF

- Q105 Esto concluye la entrevista. Antes de colgar le quisiera dar brevemente unos datos acerca del cáncer de la próstata. Al comenzar la entrevista le pregunte su opinión acerca de lo que usted piensa que hace a un hombre mas probable a desarrollar cáncer de la próstata. Creemos que es muy importante decirles a todas las personas lo que esta científicamente comprobado de causar cáncer de la próstata. Una combinación de los siguientes aspectos incrementa la probabilidad de desarrollar cáncer de la próstata.
  - Edad avanzada [mayor de 55 anos de edad]
  - Tener familiares con cáncer de la próstata como su padre, hermano o hijo.
  - Tener un familiar diagnosticado antes de la edad de 60 anos.
  - Ser Afro-Americano

Usted debe de saber que hacer ejercicio y una dieta baja en grasa puede reducir su riesgo.

- Q106 Muchos hombres piensan que otras cosas hacen a un hombre probable de desarrollar cáncer de la próstata, las siguientes ideas no son relacionadas con cáncer de la próstata.
  - Tener muchas relaciones sexuales
  - ❖ Tener demasiada tención [stress]
  - Ausencia de relaciones sexuales
  - Sentarse sobre superficies frías

Ademas, tomar alcohol no has sido comprobado científicamente de causar cáncer de la próstata.

Q107 Si quisiera mas información acerca del cáncer de la próstata, detección temprana y tratamiento, puede llamar al centro de información de cáncer. ¿Quisiera que le diera este numero?

\*\*\*\*\*

NOTE FOR Q108M:

PLEASE DISPLAY RADDRES, RCITY, RZIPCOD, RPHON\_W, AND RPHON\_M FROM RELATIVE TRACKING DATABASE

\*\*\*\*\*\*

Q108 Quisiera verificar su domicilio para poder mandarle información sobre el cancer de la prostata. También me gustaría tomar numero de teléfono de un pariente o una amistad donde lo podamos encontrar o dejar un mensaje.

(REPEAT ADDRESS AND PHONE NUMBER ON FILE- SPECIFY NEW ADDRESS AND PHONE NUMBERS (Q108M MEMO FIELD). (BLANK O.K.)

ENTER Y IF ADDRESS ETC. CHANGED, = = UPPER CASE ONLY

Q109 Si continuamos con el estudio en el fututo, ¿podríamos comunicarnos con usted de nuevo?

- 1 SI
- 0 NO
- W DK
- X RF

De parte de nuestro proyecto le agradezco su tiempo. Adiós.

## Appendix 2: Sample recruitment materials

Case recruitment: White casesCase recruitment: Asian cases

• Relative recruitment: African-American relatives

• Relative recruitment: Hispanic relatives (in English)

• Relative recruitment: Hispanic relatives (in Spanish)

# Appendix 3: Mailed questionnaire

## **UCLA Prostate Cancer Survey**

Please be assured that there are no or wrong answers. We are interested in finding out what you feel and what you believe about cancer and other issues.

1.	Please tell us your age:	years.	(Q001)
2.	Has a doctor ever told	you that you have or had prostate cance	er?
	YES(1)	NO (0)	(Q004)
prost betw	ate cancer, you do not nee een 40 and 75 years of ag	ot between the ages of 40 and 75 years ed to fill out this survey. This study is ce, AND who have never had <b>prostate</b> call is appreciated. Thank you.	only for people who are
3.		you that you have an enlarged or swolle atic Hyperplasia (BHP)?	en prostate? This is also
	YES (1)	NO (0)	(Q008)
4.	Have any of your relat	ives been diagnosed with cancer?	
	YES (1)	NO (0)	(Q011)
canc	er, (2) his/her relationship, uncle, cousin, grandfathe	ase list (1) the name of your relative who to you (for example, mother, father, si er, grandmother), (3) his/her age when conced more space, please use the back of	ster, brother, daughter, son, diagnosed with cancer, and

Name of Relative (1)	Relationship (2)	Age at Diagnosis (3)	Type of Cancer (4)
i.e. James Hill	Brother	47	Colon
	_	Marie de la companya	

# The next few questions are about screening tests for prostate cancer.

5.	One test that is done to find prostate cancer is the Digital Rectal Exam (DRE). For this test, a finger is inserted into the rectum to check for problems with the prostate and large bowel. Have you ever heard of a Digital Rectal Exam?						
	YES (1)NO (0)	(Q031)					
6.	Have you ever had a Digital Rectal Exam?						
	YES (1)NO (0)	(Q032)					
Note	: Please skip question 7, if you answered <u>NO</u> to <b>question 6.</b>						
7. W	hen was your most recent Digital Rectal Exam? Was it	(Q033)					
	Within the last 12 months (1)						
	1 to 2 years ago (2)						
	2 to 3 years ago (5)						
	3 to 5 years ago (3) More than 5 years ago (4)						
	171010 than 5 years ago (4)						
8.	The Prostate Specific Antigen (PSA) test is a special blood test that is used to che prostate cancer. Have you ever heard of a PSA?	neck for					
	YES (1)NO (0)	(Q034)					
9.	Have you ever had a Prostate Specific Antigen test?						
	YES (1)NO (0)	(Q037)					

Note	e: Please skip question	10, if	you ans	wered <u>l</u>	<u>VO</u> to <b>q</b>	uestion	9.			
10.	When was your most re	ecent P	rostate	Specific	c Antige	en test?	Was it	•••		(Q039)
	Within the las	t 12 m	onths (1)	1						
	1 to 2 years ag			•						
	2 to 3 years ag	-								
	3 to 5 years ag	gO (3)								
	More than 5 y	ears ag	gO (4)							
									- 49	
11.	Have you ever been kidneys, bladder, tes		_		ogist is	a docto	r that tr	eats dis	ease of the	ne
	YES (1)	<u>-                                      </u>	NO (	0)						(Q04
	next section is for our dential.				·			it your	answers	are
12.	What is the highest I (The numbers represanswer.)			_		_		ed. Ple	ase circle	one (Q048)
	NO SCHOOL	00								
	NO SCHOOL GRADE SCHOOL	00 01	02	03	04	05	06	07	08	
	HIGH SCHOOL	09	10	11	12	05	00	07	00	
	COLLEGE	13	14	15	16					
	POST COLLEGE	17	18	19	20					
13.	In which country we	re you	born?_					· · · · · · · · · · · · · · · · · · ·	<del></del>	(Q050)
14.	If you were <u>not</u> born	in the	<i>U.S.</i> , he	ow long	have y	ou lived	in the	U.S.?		(Q051)
	Years (Q051yy)		_Mont	hs (Q051r	nm)					

15.	Which of the following do you consider yourself to be?	(Q052)
	Black/African-American, specify(1)	
	Hispanic/Latino, specify(2)	
	Asian/Asian-American, specify(3)	
	Middle Eastern (8)	
	Eastern European (9)	
	Western European (A)	
	White/Caucasian - American (4)	
	American Indian/ Native American (5)	
	Pacific Islander (Hawaii, Guam, Samoa, other South Pacific Island) (6)	
	Mixed (Bi- or Multi-racial), specify(7)	(Q053)
	(V) Other, specify (V)	(Q052s2)
	income of all family members living with you? We do not need the exact amount, j range. And remember, your answer is confidential. Would you say approximately.  Less than \$10,000 (\$0 - \$833.33/month) (1)  \$10,000 - \$24,000 (\$833.33 - \$2000/month) (2)  \$25,000 - \$39,000 (\$2083.33 - \$3250/month) (3)  \$40,000 - \$54,000 (\$3333.33 - \$4500/month) (4)  More than \$55,000 (More than \$4583.33/month) (5)	
17.	Are you currently married or living with someone as married? YES (1)NO (0)	(Q058)
18.	What is your date of birth?	(Q058A)
	MM DD YYYY	
19.	How likely are you to ask your doctor (or nurse) about getting screened for prostate cancer?	(Q088)
	Very Likely (1) Somewhat Likely (2) Not Likely (3)	

20.	How likely are you to get a PSA blood test within the next 12 months?	(Q089)
	Very Likely (1)Somewhat Likely (2)Not Likely (3)	
21.	Have you ever participated in a clinical trial?	
	YES (1), specify	
	NO (0)	(Q093)
22.	Do you have health insurance?	
	YES (1), What type of insurance?	
	NO (0)	(Q083)
This i	s the end of the survey. If you would like to be contacted for future studies, p	olease

Nilsa Gallardo, Psy.D, Project Director
University of California, Los Angeles
Division of Cancer Prevention and Control Research
School of Public Health and
Jonsson Comprehensive Cancer Center
Room A2-125 CHS
Box 956900
Los Angeles, California 90095-6900

On behalf of our project, thank you for the time that you dedicated to the survey. Please

give us a telephone number where we can reach you. Telephone # (\_\_\_\_)

send the completed to us in the enclosed envelope.

Appendix 4: Letter to subjects requesting permission to verify screening tests

English and Spanish translation

### Letter to subjects requesting permission to verify receipt of screening tests

Date

FIELD(rfname) FIELD(rmname) FIELD(rlname)
FIELD(raddres1) FIELD(rADDRES2)
FIELD(rcity), FIELD(rstate) FIELD(rzip)

Dear Mr. FIELD(rlname):

Thank you for participating in our study on men with a family history of prostate cancer and for completing our telephone survey. Because sometimes it is difficult for people to remember all the cancer screening tests they have had, we would like your permission to contact your health care provider. We will ask for no other information other than what is listed on the form and all the information will be kept confidential. We will send you \$5 once we receive the form from you.

In order to help us complete this important prostate cancer study, we need you to do the following three things:

- 1) Sign your name and date on the enclosed form.
- 2) Write in the name, address, and phone number of your health care provider.
- 3) Return this form in the postage-paid envelope and mail it to us at UCLA. We will forward it to your health care provider.

Thank you again for your continued participation in this study.

Sincerely,

Dr. C. Bartam

Roshan Bastani, Ph.D. Principal Investigator

Enclosure

### Spanish letter to subjects requesting permission to verify receipt of screening tests

Date in Spanish

FIELD(rfname) FIELD(rmname) FIELD(rlname)
FIELD(raddres1) FIELD(rADDRES2)
FIELD(rcity), FIELD(rstate) FIELD(rzip)

Estimado Sr. FIELD(rlname):

Le damos las gracias por haber participado en la entrevista telefonica para el estudio de familiares y pacientes de cancer de la próstata. Por el hecho de que puede ser difícil recordar todas las fechas de sus análisis para el cancer de la próstata, queremos pedirle permiso para ponernos en contacto con su medico. La unica información que le pediremos a su doctor esta delineada en la siguiente forma. Toda informacion sera confidencial. Al regresar la forma que hemos incluido, le enviaremos \$5 como agradecimiento.

Necesitamos que haga lo siguiente para completar este estudio de cancer:

- 1)Firme su nombre y fecha en el siguiente documento.
- 2)Escriba el nombre, la direccion y el numero telefonico de su medico.
- 3)Regrese los documentos a UCLA en el sobre incluido. Nosotros enviaremos la documentación necesaria a su doctor.

Queremos recordarle que solamente pediremos la informacion delineada en la forma incluida que usted firmo. Toda información sera confidencial. Al regresar la forma que hemos incluido, le enviaremos \$5 como agradecimiento.

Gracias.

Roshan Bastani, Ph.D. Investigadora Principal

Sincerapiente, Ratam

Appendix 5: Letter to subjects who agreed to validation during the survey

English and Spanish translation

#### Letter to subjects who verbally agreed to validation during survey

Date

FIELD(rfname) FIELD(rmname) FIELD(rlname)
FIELD(raddres1) FIELD(rADDRES2)
FIELD(rcity), FIELD(rstate) FIELD(rzip)

Dear Mr. FIELD(rlname):

Thank you for agreeing to let us contact your health care provider in our last telephone conversation with you. Because sometimes it is difficult for people to remember all the cancer screening tests they have had, this is the best way for us to check the specific dates.

In order to help us complete this important prostate cancer study, we need you to do the following three things:

- 1) Sign your name and date on the enclosed form.
- 2) Write in the name, address, and phone number of your health care provider.
- 3) Return this form in the postage-paid envelope and mail it to us at UCLA. We will forward it to your health care provider.

We will ask for no other information other than what is listed on the form and all the information will be kept confidential. We will send you \$5 once we receive the form from you.

Thank you again.

Roshan Bastani, Ph.D.

Sincerely Ratam

Principal Investigator

Enclosure

#### Spanish letter to subjects who verbally agreed to validation during survey

Date in Spanish

FIELD(rfname) FIELD(rmname) FIELD(rlname) FIELD(raddres1) FIELD(rADDRES2) FIELD(rcity), FIELD(rstate) FIELD(rzip)

Estimado Sr. FIELD(rlname):

Le damos las gracias por habernos dado permiso para comunicarnos con su medico. Por el hecho de que puede ser difícil recordar todas las fechas de sus análisis para el cancer de la próstata, el permiso que nos da nos ayudara a obtener las fechas exactas de sus analisis.

Necesitamos que haga lo siguiente para completar este estudio de cancer:

- 1)Firme su nombre y fecha en el siguiente documento.
- 2)Escriba el nombre, la dirección y el numero telefonico de su medico.
- 3)Regrese los documentos a UCLA en el sobre incluido. Nosotros enviaremos la documentacion necesaria a su doctor.

Queremos recordarle que solamente pediremos la informacion delineada en la forma incluida que usted firmo. Toda información sera confidencial. Al regresar la forma que hemos incluido, le enviaremos \$5 como agradecimiento.

Gracias.

Roshan Bastani, Ph.D.

Investigadora Principal

Sincerarpente, Partam

Appendix 6: Verification form (English, Spanish translation)



antigen (PSA)

#### A Study of Men with a Family History of Prostate Cancer, UCLA

				PATIEN	T MEDIC	AL RELEASE
PATIENT: FIELD(rfname) F FIELD(raddres1) FIELD(rcity), FIE	FIELD(raddre	es2)_	•			
Please do the th	ree following	things:				
care provider perm dates and results of	ission to send Dr all my most rece	. Roshan B nt cancer s	astani at the UC creening test lis	spital, clinic or other CLA Jonsson Compr ted in the box below ng. A photocopy of t	ehensive Co . This auth	ancer Center the orization will be
SignatureFIELD(r	fname <u>) FIELD</u>	(rmname)	) FIELD(rlnan	Date:	IELD(rid)	_
2. Name, address a (provider with n	_	=	-	ler:		
Name: Address:						
Telephone: ()						
	o: Dr. Roshan Ba UCLA Cancer F 650 Charles You Room A2-125 Cl Los Angeles, CA	revention & ng Drive So HS/ Box 956	uth 5900			
PROVIDER (Ca						
Cancer Screening	Test (To be con	npleted by i	health care pro	vider and signed be	low)	
Test	Most Recent	Reason*	Result P= positive	Next Most Recent	Reason*	Result P= positive
Prostate specific	(Insert Date)		N= negative			N= negative

Signature:	Date:
(Health Care Provider)	

\* Reason: S=screening of asymtomatic patient or D= diagnosis of symptomatic patient

#### AUTORIZACIÓN MEDICAL PACIENTE

Pacient	te:							
FIELD	raddres1) Fl	LD(rmname) ELD(raddres )(rstate) FIEL	2)_	name <u>)</u>				
Favor d	e completar lo	siguiente:						
resultad de UCL	los de los más A. Esta autori	recientes exan zación será vá	nenes del d lida hasta	cáncer de la pro 24 meses desp	óstata a la Dra ues de la fecha	. Roshan l a indicada	ación sobre las fe Bastani en el cen con mi firma al da que la origina	tro de cáncer menos que yo
	Firma:			_ Fe	cha:			
	FIELD	(rfname) FIE	LD(rmna	Fed me <u>) FIELD(</u> rlı	name <u>) FIEL</u> [	)(ptid)-FI	ELD(rid)	
2) Nombre, Dirección y numero telefónico de mi doctor/a: (El doctor que tenga lo más de sus datos médicos)					<ol> <li>Envie la información a:         Jonsson Comprehensive         Cancer Center     </li> </ol>			
Nombre	e:					Box 9		
Direcci	ón:						ngeles, CA 9009 I: Dra. Roshan B	
Numero	o Telefónico: (			<del></del>				
Exame	nes Prelimina	arios (Esta poi	cion deb	e ser llenada p	or su doctor/	a):		
	Examen	Fecha (más reciente)	Razón	Resultado P=positivo N=negativo	Fecha (segunda más reciente)	Razón	Resultado P=positivo N=negativo	
	ASP							
Razón: S= Examen de un paciente sin sintomas D= Diagnosis de un paciente con sintomas								
Firma:				Fecha				
	(Firma del doc	tor/a)						

Appendix 7: Letter to providers requesting validation of self-report

#### Letter to Providers

Date

Name Address

Dear Dr. Name:

Your patient << Patient Name >> has signed a release form for us to obtain the dates of their most recent prostate specific antigen (PSA) cancer screening test. (See enclosed form). This is an important part of our study of men with a family history of prostate cancer, in which your patient is enrolled. (See enclosed abstract.) We need this information to validate the screening information your patient gave us over the telephone.

We have enclosed \$10 to help offset the cost of obtaining this information. The enclosed signed release form is also the record abstraction form for your office staff to fill out and return to us in the postage-paid envelope. Alternatively, you or one of your staff may call and give us the information over the phone or leave it on our voice mail at the following number: (877) 278-8506. If you have any questions about this study, please do not hesitate to call me.

Thank you for your assistance.

Sincerely,

Roshan Bastani, Ph.D. Principal Investigator

Enclosure

"You are key to the health of your family"

#### A note to you:

Lealthy Families research study. This study aims to catch prostate cancer early and save lives.

#### Why am I key?

# You are key because you have had prostate cancer.

The men in your family are more likely to get prostate cancer than men who have no prostate cancer in their family. The Healthy Families Project wants to develop new programs to help fight prostate cancer in close family members. We need your help in contacting your father, brothers and adult sons, even if they do not have prostate



## What will I need to do?

#### All you need to do is:

- Fill out the attached Family Information Form.
- 2. Return the form in the enclosed stamped envelope.

# What will my family members need to do?

telephone interviews. If they agree, we will ask them about what they know and how they feel about prostate cancer and its early detection.

## What will happen to the information my family members provide?

W programs to fight prostate cancer in close family members.

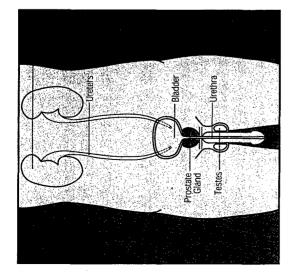
## Do I need to participate?

family's health. Your participation is voluntary and all information will be confidential. There is no cost to you to participate. Your choice to take part will not affect the services you receive from your doctor or the Los Angeles County Cancer Surveillance Program. If you do not want us to call you or your family members, just mark the box on the form that says "I do not want to participate" and return it in the enclosed envelope.

# Who can I call if I have questions?

V ou may call us toll-free at (877) 278-8506. We will be happy to answer your questions.

"You are key to the health of your family"



The prostate is a gland found only in men. It produces a thick fluid that forms part of the semen. The prostate is about the size of a walnut. It is located below the bladder. The prostate surrounds the upper part of the urethra, the tube that empties urine from the bladder.



io thie health on Wow family!

con aire key

Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.



Los Angeles County Cancer Surveillance Program, a
member of the California Cancer Registry.
 Every cancer diagnosed in California is required by
law to be reported to the California Department of
Health Services, which is responsible for the registry.
 Information on individuals with cancer can only be
released for research purposes to qualified
researchers who have obtained approval for the
study from a federally approved Committee for the
Protection of Research Subjects.

Jonsson Comprehensive Cancer Center
Division of Cancer Prevention and Control

650 Charles Young Drive South Room A2-125 CHS Box 956900 Los Angeles, CA 90095-6900





"You are key to the health of your family"

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## What will I need to do?

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- 2. Return the form in the enclosed stamped envelope.

What will my family members need to do?

will call your family members to ask them to participate in telephone interviews. If they agree, we will ask them about what they know and how they feel about prostate cancer and its early detection.

What will happen to the information my family members provide?

W e will use it to develop new programs to fight prostate cancer in close family members.

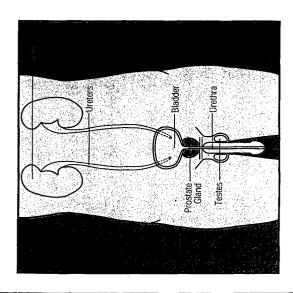
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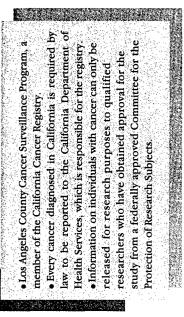
"You are key to the health of your family"



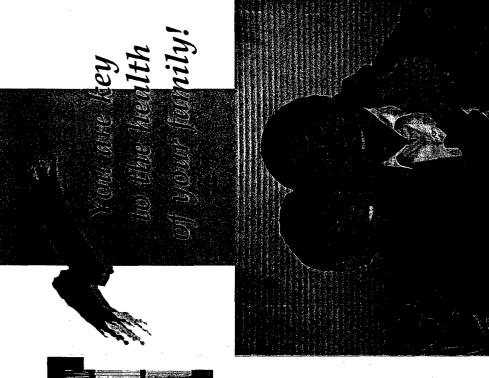
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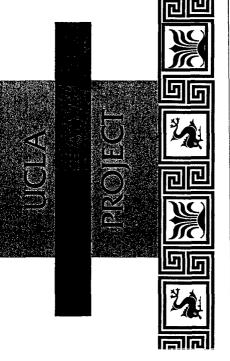


Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.



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## "You are key to your health"

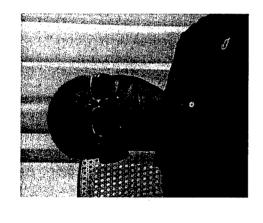
#### A note to you:

V ou can help in the fight against prostate cancer by joining in the **Healthy Families** research study. This study aims to catch prostate cancer early and save lives.

#### Why am I key?

You are key because someone in your family has had prostate cancer.

L higher risk of getting prostate cancer than men who have no prostate cancer in their family. We at the **Healthy Families** Project are committed to recruiting African American men such as yourself. This is so that we can get information on your special needs and concerns. The information you



provide will be used to develop new programs to fight prostate cancer in close family members.

## What will I need to do?

#### All you need to do is:

ake part in a 20 minute telephone interview. We will ask you questions about what you know and how you feel about prostate cancer and its early detection.

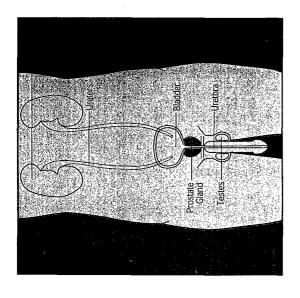
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# Who can I call if I have questions?

V ou may call us toll-free at (877) 278-8506. We will be happy to answer your questions. If you have more questions, thoughts, or concerns, you can write the Office for Protection of Research Subjects, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095, (310) 825-8714.

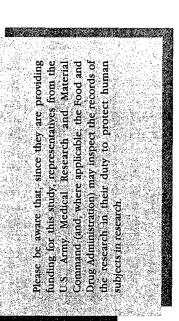
"You are key to your health"



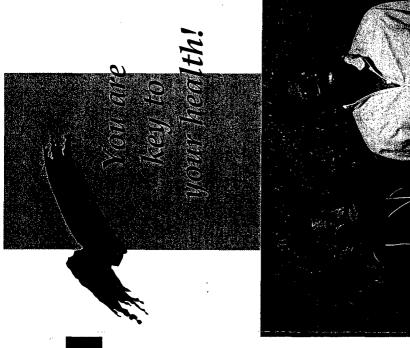
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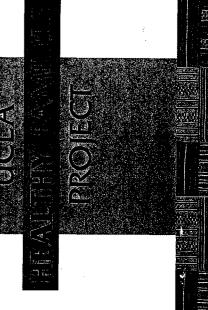


Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.



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"Usted es clave para su salud"

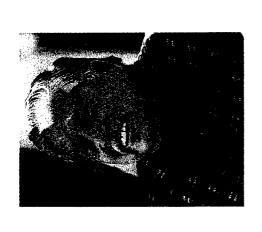
#### Una nota para usted:

Este estudio aspira detectar cáncer de la prostata uniendose al estudio de investigación Familias Saludables. Este estudio aspira detectar cáncer de la prostata temprano y asi salvar vidas.

## ¿Por que soy yo clave?

#### Usted es clave porque alguien en su familia ha tenido cáncer de la prostata.

mas alto riesgo de desarrollar cáncer de la prostata que personas que no tienen cáncer de la prostata en su familia. Nosotros en el Programa de Familias Saludables estamos comprometidos a reclutar hombres hispanos como usted para obtener información en especial sobre sus necesidades y preocupaciones. La información que



usted proporcione sera usada para desarrollar nuevos programas para combatir el cáncer de la prostata en familiares cercanos.

## ¿Que tendré que hacer?

# Lo unico que usted tiene que hacer es:

articipar en una entrevista telefónica de 20 minutos. Le haremos preguntas acerca de lo que sabe y siente sobre el cáncer de la prostata y su detección temprana.

## ¿Tengo que participar?

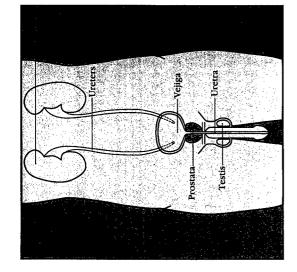
o, pero esperamos que lo haga por su salud y la de su familia. Su participación es voluntaria y toda la información sera confidencial. No hay ningun costo para participar. Si usted no quiere participar por favor marque la caja que dice "Yo no quiero participar" en el formulario y regreselo en el sobre adjunto. Usted puede dejar de participar en el estudio en cualquier momento.

# ¿A quien puedo llamar si tengo preguntas?

al numero (877) 278-8506. Estaremos encantado/as de contestar sus preguntas. Si tiene mas preguntas, opiniones, o inquietudes, usted puede escribir a la Oficina de Protección a Sujetos de Investigación, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095, (310) 825-8714.

"Usted es clave para su salud"

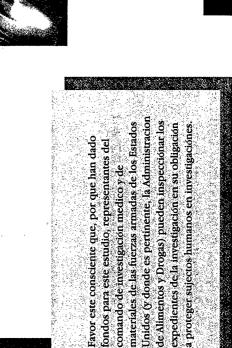
# Detección Temprana



La prostata es una glandula que se encuentra solamente en los hombres. Ella produce un liquido espeso que forma parte del semen. La prostata es mas o menos del tamaño de una nuez. Esta localizada bajo la vejiga. La prostata rodea la parte superior de la uretra, el tubo que vacia la orina de la vejiga.



Equipo conduciendo el Programa para la Prevención del Cáncer de la Prostata. De izquierda a derecha: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.



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"You are key to your health"

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#### Why am I key?

# You are key because someone in your family has had prostate cancer.

higher risk of getting prostate cancer than men who have no prostate cancer in their family. We at the **Healthy Families** Project are committed to recruiting Hispanic men such as yourself. This is so that we can get information on your special needs and concerns. The information you provide will be



used to develop new programs to fight prostate cancer in close family members.

## What will I need to do?

#### All you need to do is:

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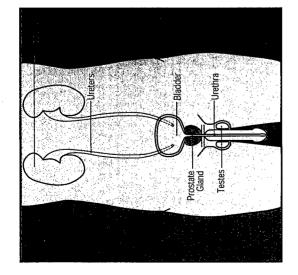
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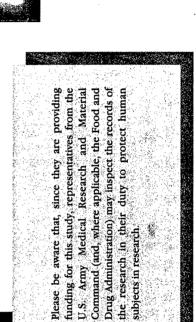
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ivision of Cancer Prevention and Com 650 Charles Young Drive South Room A2-125 CHS Box 956900 Los Angeles, CA 90095-6900







#### DEPARTMENT OF THE ARMY US ARMY MEDICAL RESEARCH AND MATERIEL COMMAND 504 SCOTT STREET FORT DETRICK, MD 21702-5012

MCMR-RMI-S (70-1y)

15 May 03

MEMORANDUM FOR Administrator, Defense Technical Information Center (DTIC-OCA), 8725 John J. Kingman Road, Fort Belvoir, VA 22060-6218

SUBJECT: Request Change in Distribution Statement

- 1. The U.S. Army Medical Research and Materiel Command has reexamined the need for the limitation assigned to technical reports written for this Command. Request the limited distribution statement for the enclosed accession numbers be changed to "Approved for public release; distribution unlimited." These reports should be released to the National Technical Information Service.
- 2. Point of contact for this request is Ms. Kristin Morrow at DSN 343-7327 or by e-mail at Kristin.Morrow@det.amedd.army.mil.

FOR THE COMMANDER:

Encl

Deputy Chief of Staff for Information Management

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